



# Working with Dads: Resources and Support for Fathers of Children with Special Needs

July 25, 2013



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Responsible  
Fatherhood Clearinghouse  
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# National Responsible Fatherhood Clearinghouse Overview

- Office of Family Assistance (OFA) funded national resource for fathers, practitioners, programs/Federal grantees, states, and the public at-large who are serving or interested in supporting strong fathers and families.
- NRFC Director: Kenneth Braswell, Sr.  
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# National Responsible Fatherhood Clearinghouse

- Visit the NRFC: [www.fatherhood.gov](http://www.fatherhood.gov)
  - [www.fatherhood.gov/toolkit](http://www.fatherhood.gov/toolkit) for *Responsible Fatherhood Toolkit*.
  - [www.fatherhood.gov/webinars](http://www.fatherhood.gov/webinars) for archives of all our webinars.
- Contact any of our staff: [info@fatherhood.gov](mailto:info@fatherhood.gov)
- Encourage fathers or practitioners to contact our national call center toll-free at **1-877-4DAD411 (877-432-3411)**.
- Engage with us via social media:  
**Facebook: [Fatherhoodgov](https://www.facebook.com/Fatherhoodgov) Twitter: [@Fatherhoodgov](https://twitter.com/Fatherhoodgov)**
- See website for information on the *President's Fatherhood and Mentoring Initiative* and NRFC *Fatherhood Buzz* events.
- Look for examples of our *Annual Media Campaign* designed to promote the Responsible Fatherhood field.





# National Responsible Fatherhood Clearinghouse Overview

Resources are available for:

- **Dads** looking for tips, hints & activities for dads and kids (see *DadTalk Blog* and "*For Dads*" corner).
- **Fatherhood programs** looking to get started or expand (check out "*For Programs*" and *webinars*).
- **Researchers and policy makers** looking for the latest on responsible fatherhood (search our *Library*).



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Greg Schell, Director  
Washington State  
Fathers Network

July 25, 2013



# Why be concerned with dads having children with special needs?

- The U.S. Census (2010) identifies 1 out of 5 individuals in the U.S. as having a significant disability.
- It is inevitable there will be dads in your programs having disabilities themselves, and also some having children with disabilities.
- Preparing effectively to meet, interact with, and support dads having special needs or children with special needs will take some planning.





# Washington State Fathers Network (WSFN) - What we do

- 17 chapters in Washington state
  - Led by volunteer dads
- Dads talking with other dads
- Social activities for dads and their families
- “Unexpected Journey”
  - 8-week series of groups to help new moms and dads prepare for the journey
- Referral arrangements with family therapists (who have special needs child of their own)



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# Washington State Fathers Network (WSFN) - Program Outcomes

- In 2012, the University of Washington-Bothell conducted a cross sectional study to determine outcomes for WSFN program participants.
- 146 members responded to 38 online survey questions. Data collected led the researchers to conclude that WSFN participation had substantial positive effects.
- Fathers reported the following:
  - Anxiety decreased 97%
  - Feelings of hopelessness decreased 57%
  - Enthusiasm towards their child increased 69%
  - Feelings of joy increased 67%
  - Family relationships improved 77%
  - Having someone to relate to increased 80%



Knowledge of different kinds of grief may be helpful in supporting all kinds of dads

- Typical grief process is not so typical.
- Research has shown stress levels in families having a child with special needs is usually much higher than typical families.
- Cyclical (or Recurrent) grief.
- Chronic grief.
- Incongruent grief.



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# Divorce and Families with Special Needs: the Myth Continues!

- Modern media regularly perpetuates the idea that divorce rates for couples who have children with special needs is extremely high compared to typical families.
- The reality is very different!
  - Divorce rates are nearly identical to typical families.
  - Remember however, divorce rates are quite high for typical families - somewhere between 37% and 43% in first marriages.
- In two very large studies on divorce, one at Vanderbilt University, and one at Kennedy Krieger Institute, this myth is debunked.



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# Research Citations: divorce rates for families with special needs children

From Vanderbilt University (2007):

- *Divorce in Families of Children With Down Syndrome: A Population-Based Study*, Journal on Mental Retardation (Vol. 112, No. 4, July 2007), Richard C. Urbano & Robert M. Hodapp, Vanderbilt Kennedy Center, Nashville, TN.

From Kennedy Krieger Institute (2010):

- <http://www.kennedykrieger.org/overview/news/80-percent-autism-divorce-rate-debunked-first-its-kind-scientific-study>
  - 2007 National Survey of Children's Health - nationally representative sample of 77,911 children, ages 3 to 17.
  - 64 percent of children with an autism spectrum disorder (ASD) belong to a family with two married biological or adoptive parents, compared with 65 percent of children who do not have an ASD.



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# One more research article

- Dyer, W. Justin, McBride, Brent A., and Jeans, Laurie M. A Longitudinal Examination of Father Involvement With Children with Developmental Delays: Does Timing of Diagnosis Matter? *Journal of Early Intervention*. (Vol. 31, No. 3, June 2009)
  - The involvement with their children for dads of children with special needs is very similar to that of typical dads.



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# Resilience is a major focus of the work we do at WSFN

Helen Keller provides a provocative insight into the attribute of resilience:

- *“When one door of happiness closes, another opens; but often we look so long at the closed door we do not see the one which has been opened to us.”*





# A Challenging Question for All Dads:

Are you the dad you would want if you were your child?



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# Contact Information

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Wilfried C. ("WC") Hoecke, Director  
Family Information and Education  
Family Connection of South Carolina  
July 25, 2013



# Two tasks for a family with a new diagnosis:

1. “Each family must make a place for the disability in their family.”
2. “Each family must put the disability in its place.”

Bill Doherty



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# A closer look at the Process of Grief





# 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's and the services received.
  - Fathers typically receive information second hand.
  - Some fathers report difficulty having their wives being their teacher.
  - Fathers report they often feel relegated to being the hunter provider.



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# 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 approaches are needed.



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# Fatherhood Survey Results

August 2009

Responses from 109 fathers



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# What topics of information are you interested in?

## 1. Taxes

- Tax write-offs per special needs law.

## 2. Advocating for your child

- Changing laws to benefit your child, fighting discrimination against disabled people.

## 3. Special needs trust/wills.

## 4. Financial issues.

## 5. Relational stress.

## 6. Discipline/behavior management.

## 7. Therapies (PT/OT/Speech).





# Topics of interest (cont.)

8. Medicaid/ insurance.
9. Keeping child safe, prevention of abuse and neglect, internet safety.
10. IEP/IFSP.
11. Communication with providers.
12. Communication skills with mother of child.
13. Sibling issues.
14. Creating Circle of Support with family members and friends.
15. Recreation, Special Olympics.
16. Nutrition.
17. Respite care (taking a break from care giving).
18. Conflict resolution with mother of child.
19. Housing and employment
20. Transition out of school.
21. De-escalation with mother of child.



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## Response from dads not using Family Connection services:

### What prevents you from using our services?

- Work schedule
- Time
- I thought your organization was only for women
  - “Parent” often associated with Mother -- e.g. Parent Teacher Association (PTA)



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## Key motivation factors that encourage involvement with child

- Satisfaction in seeing child achieve.
- Positive response from child.
- Positive response from child's mother.
- Seeing learning occur, academic requirements met, help with homework.
- The desire to see my child accepted.

### Preferred meeting format

- Family events
- Topic related workshop
- Group meetings for dads only





# Contact Information

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# Being the Right Dad of a Children with Special Needs

Ray Morris  
Dads 4 Special Kids  
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July 25, 2013



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The logo for the National Responsible Fatherhood Clearinghouse is located in the bottom left corner. It features a stylized line drawing of a family consisting of a man, a woman, and a child. Below the drawing, the text "National Responsible Fatherhood Clearinghouse" is written in a sans-serif font, followed by the website address "fatherhood.gov" in a smaller font.

# The Morris Family

Ray & Kelly Morris

27 years

Sons

Zachary: 25 yoa

Hemimegalencephaly

Tyler: 23 yoa

Engineer/Paramedic



Dads 4 Special Kids Inc.





# My dad, Ray

Impaired Driver 1969

Quadriplegic

Passed away in 2001

“It’s hard to get someone to talk to me being in a wheelchair, so I have to have to be positive.”

“I’m still a man, this chair doesn’t define me.”



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**“Life is not fair,  
but I have a choice  
in how I respond.”**

“My attitude is the only thing  
I can control”



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# Zachary Isaac Morris

June 24, 1988

Hemimegalencephaly: Right side of brain larger than left

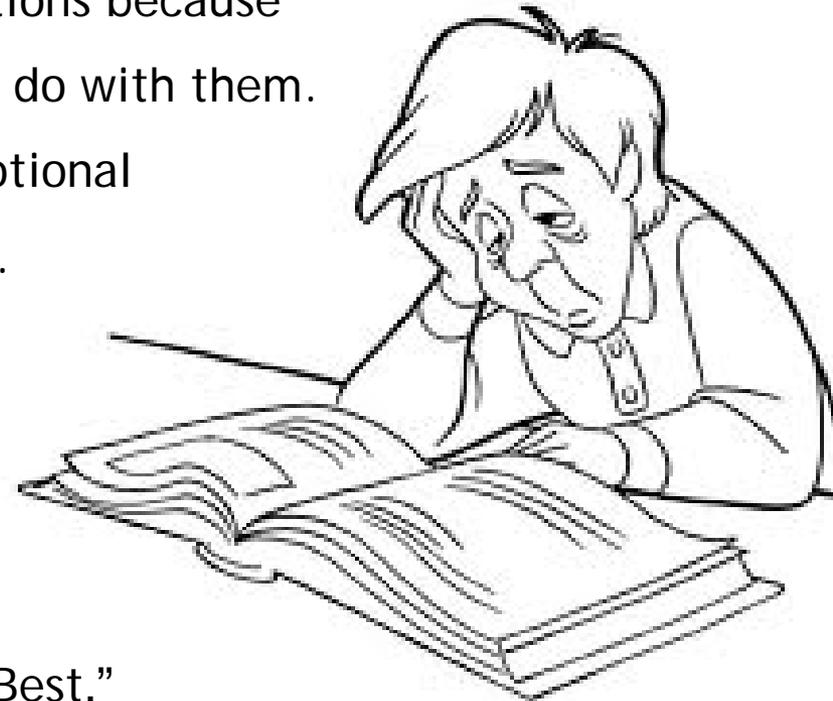
Dr. said: "He will have uncontrolled seizures, there's nothing we can do. So come back when he starts having seizures, then we'll remove half his brain."





# I didn't handle it very well

- ✓ I went into “survival mode” - what I learned as a child.
- ✓ I focused on work and meeting the material needs of the family.
- ✓ I left Zach's doctor appointments, therapy, advocacy to Kelly.
- ✓ I was emotionally disconnected from life at home.
- ✓ I couldn't handle Kelly's emotions because I didn't know my own or what to do with them.
- ✓ I had to identify my own emotional pain; learn how to find meaning.



I hadn't learned to accept that  
I hadn't been wronged in life  
and that God has given us “His Best.”



But this isn't the

***Son,***

I dreamed of !

Yet I'm his dad, so I must be the  
right dad for him &  
he's the right son for me

I might as well trust God  
And grow into the father he & my family need



# The search begins with me

- I know there is a reason, but I hurt.
- I didn't know how to express my feelings.
- All I had been taught was how to survive.
- How should a man respond to something like this?
- ✓ Cry? Leave? Ask for help?
- ✓ There was no one to guide me, I was alone.





# Things I've learned

- I have a choice.
- I can be angry.
- I can be content.
- I can allow life to change me and grow.
- I can find the good in it.
- I can let it take away my joy, my life, my love and my ability to be loved.
- Learn from other dads.



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# Dads 4 Special Kids (DFSK)

- Born from my own pain, searching & experience.
- Learned that there are other dads, struggling.
- We can learn from each other, their strength in numbers.
- We experiences validate each others journey.
- We have to take care of ourselves, our marriages.
- There is little support for marriages that have a child with special needs:
  - less than 10% of all funding goes towards 'family support.'



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# What does D4SK do?

- Make the journey with dads, “no man should be alone.”
- We have monthly support meetings.
- Dad to Dad support.
- Emergency/Disaster Preparedness Workshop.
- Advocate for dads and what they need.
- Marriage/Relationship Support.



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# Marriage Support

- Having a child with special needs can put a strain on even the most solid marriage.
- Many parents lose their personal identities and relationship priorities because so much attention is spent on their child.
- Couples need to remember who they are as individuals and relationship partners.
- Through coaching, guidance, and support offered by Resilient Relationships, LLC, parents can learn to manage stress and communicate better, thereby fostering and maintaining personal care and resilient relationships.



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# Approach of Dads 4 Special Kids

- 4-5 month workshops with 5-7 couples who have children of similar ages:
  - 3 hour group workshops plus individual counseling
  - Some web based contact
  - Power of peer support.
- Dad only workshops - help each other.
- Graduates become mentors for future groups.



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# Contact information

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# Additional Resources

- *Exceptional Parent* - [www.eparent.com](http://www.eparent.com)
  - Monthly magazine of practical advice, emotional support, educational information for families, + health care and educational professionals.
- *Uncommon Fathers: Reflections on Raising a Child with a Disability*
  - Book by Donald Meyer with stories by dads for dads.
- The Arc - [www.thearc.org](http://www.thearc.org)
  - National community-based organization serving people with intellectual and developmental disabilities and their families (chapters in most states).
- Dads Appreciating Down Syndrome (DADS) [www.dadsnational.org](http://www.dadsnational.org)
  - 57 U.S. chapters - "We came together for our kids. We stay together for each other."
- Family Voices - [www.familyvoices.org](http://www.familyvoices.org)
  - National network with focus on family centered care for children and youth with special health care needs, helps families make informed decisions, and advocates for improved public and private policies.