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## **Introduction**

As the field of Fatherhood is increasing, a large subgroup of fathers of children with special healthcare needs is going unnoticed, yet it represents twelve to eighteen percent of all fathers in the United States.<sup>1</sup> Service deliver best practices are beginning to emerge for subgroups such as, non-custodial fathers, teen fathers, incarcerated fathers, under-employed, unemployed and fathers in general. Although research on Children and Youth with Special Health Care Needs (CYSHCN) is also increasing, minimal documentation has been produced on their fathers as a subgroup. This paper emphasizes the need for targeted funding, updating federal and state policies, assimilation and dissemination of promising practices on fatherhood to serve the field of practitioners and emerging fatherhood networks.

After years of unfortunate vacancy, research aimed at fathers with children with special needs is thankfully on the rise as the father's role in child development has moved closer to center stage. However, the research acquired within this population of fathers show contradicting results. With this in mind, our approach will

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<sup>1</sup> Bethell, C.D., D. Read, D. J. Blumberg and P.W. Newacheck.” What is the prevalence of children with special health care needs:” Toward an understanding of variations in findings and methods across three national surveys.” Maternal Child Health Journal. 2008 Jan 12(1): 1014. Epub 2007 June 14.

1. offer a broader perspective as we look at these fathers and their needs;
2. will recount observations by general practitioners in the field and lessons learned directly from the field of practice as practitioners seek to integrate service delivery methods;
3. will highlight philosophies and personal observations gleaned during countless hours of service delivery should be shared;

In conclusion, will offer practical, tangible steps for fatherhood programs, curriculums, presentations and networks.

The tone of this article is purposefully optimistic; and, that is a unique distinction emanating from this author and sources contributing to the paper. These colleagues not only work with the fatherhood population, but are themselves fathers of CYSHCN with first hand knowledge of the extraordinary benefits of positive, continuous support.

Positive outcomes increase significantly when systems are in place to support fathers, the results of which naturally benefit children. Common threads and consistency have been observed in service delivery to fathers and reported in smaller studies like those by Vickie Turbiville (2001) and Deborah Lane (2004).<sup>2</sup>

### **Broad Perspective: CYSHCN Father Population Profile**

Each father confronted with their child's diagnosis responds in his own unique way often displaying a range of emotions including lack of understanding and fear. Practitioners working

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<sup>2</sup> Turbiville, V.P., Marquis, J. G. (2001). "Father participation in early education programs." Topics in early Childhood Special Education, 21 (4), 223-231.

with fathers often report document aspects of these four experiences: (1) loneliness and isolation; (2) hunter provider anxiety; (3) strained marital relationships and (4) saint syndrome.

### Loneliness and Isolation

Fathers may experience a sense of isolation from many of their natural relationships even prior to receiving their child's diagnosis. As Lane says in her writing:

“Fathers of children with special needs oftentimes feel isolated, and this can be the result of several factors. First, it is simply typical of men's social nature to have fewer supports in place than do women. For some fathers, embarrassment of a child's lack of developmental appropriateness can further contribute to feelings of isolation (May, 1991). Fathers of special needs children who might be delayed in their development may feel their child's accomplishments are insignificant when compared to typical children of friends and coworkers. The difficulty in conveying the importance and magnitude of such accomplishments may result in keeping the stories to oneself – again, subscribing the feelings of isolation (May, 2002).”<sup>3</sup>

One father in a 2001 *Fathers Network* meeting in Columbia, South Carolina reported, “All the other dads at the lunch table talked about how successful their kids were in their little league football games over last weekend; and, I'm just thrilled my son is out of pull-up diapers.” Families and friends who lack experience or knowledge of CYSHCN may unintentionally increase the father's sense of isolation and loneliness.

### Hunter-Provider Anxiety

Much has been said and written about the traditional, archetypal role of hunter-provider practiced by many fathers in family relationships. However, for a father of a CYSHCN these traditional roles may be challenged. In a safe, sharing environment fathers openly express feelings of inadequacy to provide for their families. Large financial investments for specific medical and therapeutic care are often required and perceived as necessities for special needs

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<sup>3</sup> Lane, Deborah Jean, “Assessing the Needs of Fathers with Children with Down Syndrome,” (dissertation), Columbia, SC: Committee of Department of Obstetrics and Gynecology, School of Medicine, University of South Carolina. 2004.

children to meet optimal potential. Men also report feelings of anxiety and being ill-equipped to satisfactorily balance work, home and multiple roles as fathers, husbands and providers.

### Strained Marital Relationships

It has been reported that mental health treatment for stress is two to three times higher for parents of children with special health care needs (Cadman).<sup>4</sup> This is poignantly exemplified in a comment from a father at a *Fathers Network* meeting in Columbia in 2006:

“I feel like my wife is having ‘an affair’ with my daughter. My child sleeps with her in my place in our bed because she needs suctioning every half hour. I am angry with my daughter because I don’t get any physical intimacy or attention from my wife. Now, I feel guilty for being angry with my daughter because she has done nothing to deserve my anger. What kind of father am I to feel this way? Now, I am angry with myself.”

In 2005 a focus group to help men reduce stress was conducted by the Father’s Network in South Carolina. During the session the facilitator repeatedly asked group members the following question, “What was it or is it about your special needs child that causes you the most stress?”

One hundred percent of the responses were the same. The fathers did not view their child as the source of their stress; indeed, the fathers embraced their special needs child as one of the best things that had ever happened to them. The men reported that their greatest source of stress was trying to meet the needs and expectations of their wives and significant others. “What do you do when she cries for two hours; and, you can’t fix it; or, she wants to spend all we have on a new therapy?” one of the fathers queried.

Although marriages and relationships experience high stress the 80% divorce rate reported prior to 2010 is completely inaccurate. Studies by the Center for Autism and Related Disorders at

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<sup>4</sup> Cadman D, Rosenbaum P, Boyle M, “Children with Chronic Illness: Family and Parent Demographic Characteristics and Psychosocial Adjustment.” Pediatrics. 1991, June:87 (6 ): 884-9.

Kennedy Krieger Institute in Baltimore, MD and The American Journal on Mental Retardation, in separate studies, both found only a one percent difference in divorce rates between families with special health care needs children and those not having special health care needs. Other factors, such as youthfulness of parents, lower education levels and living in rural areas were more likely to influence divorce decisions.<sup>5</sup>

### Saint Syndrome

“My wife has become a super saint,” commented a father during a Fathers’ Network meeting in 2006. Fathers reported struggling with being the recipient of constant instruction from their wives (or the child’s mother). One father said, “I didn’t marry her for her to be my educator. She knows all the issues related to my child’s disability. She educates me about all the new pieces of research she is learning. I feel that I can’t compete with her level of informational knowledge about my child’s disability, treatments or knowledgeable care for my child.”

Fathers may experience stronger feelings of isolation when their wives and/or parenting partner projects the “saint syndrome” and/or “super educator” persona. This scenario is supported in a study by E. Herbert in 1995 which Lane uses to highlight reports that fathers feel that their perspective is often overlooked or ignored in dealing with the issues related to their child. Particularly, fathers felt that learning second-hand information from the mother hampered their ability to openly express concerns, relay feelings and worries about their child to their spouse or significant other (Lane, 17).<sup>6</sup>

### A Father’s Testimony

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<sup>5</sup> Kennedy Krieger Institute, Baltimore, MD. Studies by the Center for Autism and Related Disorders and The American Journal on Mental Retardation.

<sup>6</sup> Lane, Deborah Jean, page 17.

The following excerpt was written by this author and is installed as a section of the resource guide provided to fathers newly joining the Fathers Network of Family Connection of South Carolina. For this author, birth of a first child heralded this news. This excerpt provides a more personal picture of a father's experience and perspective.

It was as if someone had given me a sucker punch in the gut that took the wind right out of me: the words *Down syndrome*. I was forced into an arena and told to play a game that I knew nothing about and, frankly, had no desire to play. I hadn't trained and wasn't conditioned for it. I didn't even know the rules. I had envisioned a totally different game. But now my blue-eyed boy beckoned me to come and play.

Men thrust into this game will play it very differently. Some will be solo runners. They just want someone to show them the court and give them the ball and get out of their way. Others want a coach. Not someone who thinks they're better than them, but someone who has played the game before and can share the rules with them. The reality is that coaches know they are usually in the presence of better ball players than themselves. However, a coach knows the rules and how to work the field to the player's advantage. He may even be able to let you know where other sucker punches come into play. Other dads want a team or a group of men who play the game together. Another select few will opt to forfeit the game and not play at all. The choice must be made by each father. I just know that when I chose to answer my child's call to 'come out and play,' I began to travel down one of the most rewarding roads I have ever traveled.

I have talked with hundreds of dads. One thing we all have in common is the sense of the loss of the dream we had of what our child may do and be. The reality is that few, if any of us, met the expectations of our own fathers. I never became the engineer that my father expected; you may not have been the ball player your dad anticipated. However, our parents had twenty to thirty years to discover that their dreams would be redirected. I had to digest this reality in the time it took someone at the hospital to say *Down syndrome*. The loss of this dream is real; and, it is quite natural to be upset.

Although I am not the engineer my dad wanted me to be, my parents', especially my dad's, encouragement has been the most significant factor in realizing the dreams that I have realized for myself. Your role, as father, is even more significant now. I have learned to take life at a little slower pace. I understand so much better the stages of development and how each builds on the next. You will hear a lot of us say that our children have made us much better fathers than if we had not experienced this world of disabilities.

Please understand that your child will succeed in the things they choose to accomplish. Some of our children are holding down full-time employment, attending college, authoring books, and even getting married. Others may never meet those goals. Will my child reach those goals? No dad really knows; and, for me 'having to wait and see' is the hardest part of being a dad. Our children may amaze us with the things they are interested in and the dreams they will realize for themselves.

A realistic objective is to help them walk through all of the developmental stages to achieve their dreams. You have the opportunity to learn and understand all of the developmental stages that it takes to fulfill their dreams. We believe that information is power; and, you and your child have the power to succeed in whatever endeavors you take on (Father's Resource Guide, Fathers Network of Family Connection of South Carolina, *section 7.0.3*).<sup>7</sup>

## **Observations and Promising Practices**

Having described four unique attributes of fathers of CYSHNC the next step is to present **observations and definitive recommendations** for changes in service delivery methods which capitalize on a clearer understanding of this population. By personalizing the learning environment to male participants it is anticipated that their coping mechanisms will expand, the impact of loneliness and isolation will be lessened, hunter-provider anxiety will reduce, understanding concerning marital relationship stressors will change and occurrence of saint syndrome will be understood.

The service delivery recommendations presented in this paper have been field tested and resulted in very positive feedback with this unique fatherhood population. It is hoped that sharing best practices in this paper will encourage other practitioners to assimilate them into their own curriculums and disseminate results across this network.

Below are descriptions and examples for seven service delivery methods. Highlights and anticipated results with each implementation are also noted.

### **Select Terminology Implying Strength**

Practitioners across the globe have experienced impressive increases in attendance by merely changing descriptors in promotional materials. Artful selection of program descriptors can be a key to attracting male audiences. For example the term, “support group,” implies

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<sup>7</sup> Fathers Network of Family Connection of South Carolina, “Father’s Resource Guide.” Section 7.0.3.

weakness and failure, negatively affecting many males. Marketing meetings as a “fathers’ network” creates a shift in perception re-branding them as success-oriented opportunities for fathers to exchange information and experiences with one another. This is a strengths-based model which has proved highly successful in distinguishing program services. Another strength-based term positively recognized by men is “coach” or “mentor.” Programs that replace the term “support parent” for “coach” or “mentor” are more likely to observe positive responses from fathers and an increased willingness to interact with other fathers. These seemingly simple terminology changes resonate with the target male audience and play to their perceptions of strengths making them valuable enhancements to promotions and curriculums.

## Men as Fixers and Problem-Solvers

The male gender has a natural propensity to “fix” things whether that involves hands-on action or calling a qualified repair person. As with altering promotional terminology, we recommend curriculums and programs that demonstrate fathers’ consistent, defined contributions with tangible results for the well-being of their child. Implementing this methodology addresses the question, “So, what do you want me to do?” It capitalizes on natural instincts and increases the likelihood of fathers accessing program services and resources. This author, father of a 19 year old CYSHCN, admits to continuously learning about not fixing or “remedying” his son’s disability. His most powerful discoveries have been the myriad of ways to contribute to improving his child’s outcomes. Within the first year of diagnosis, most fathers appreciate information and insight about improving outcomes for their child; and, it often translates into consistent, long-lived participation in the child’s life, a pattern not always evident when the mother “takes over” in the child’s care-giving plan. Teaching methods for improving the results of outcomes is a more viable, results-oriented deliverable for fatherhood programs.

## Introduce Fathers to Advocacy

This population of fathers may never have pictured themselves as advocates; however, once introduced and armed with understanding and information, their natural response to the statement, “Tell me what to do,” may give birth to a new assembly of advocates. Fathers of CYSHCN are often new to parenthood and to disabilities. Overflowing with questions, they want to give and receive information; but, may have limited experience in sorting and discerning the barrage offered to them. Their knowledge gap is reflected in the results of a (South Carolina) statewide survey of fathers with CYSHCN which found that the second most popular information request topic was advocacy methods for healthcare and disability rights. To reduce

their knowledge gap and inspire them toward action fatherhood programs should collect information on exemplary state and national programs and introduce them to their clients. One such program is D.A.D.S (Dads Appreciating Down Syndrome) which engages fathers by using email to contact local lawmakers for the purpose of advocating improved state laws to benefit children with Down syndrome. This organization has also developed a forum for fathers to communicate with one another (<http://www.dadsnational.org/>). Not only will the fathers realize valuable information; but, it may also inspire them to initiate their own networks and methods of advocacy.

### Uniqueness of Fathers as Nurturers

We must consciously demonstrate and give voice to the appropriate, yet varied, ways that fathers parent and display caring for their CYSHCN. Physical play is a proven way that men display affection for their children; and, it provides opportunities to demonstrate their feelings and to experience incredible fulfillment and pride. Yet, mothers often respond negatively to fatherly pre-bedtime tumbling and wrestling viewing it as over-exciting the children at the end of the day. Through insightful program additions fathers can learn and receive reinforcement that both nurturing through play and motherly cuddling are appropriate. Interestingly, outcomes are very similar for children between physical play and cuddling since both are perceived as demonstrated affection. Promising additions to fatherhood curriculums include offering demonstrations of physical play honing in on the pros and cons as related to age levels and physical limitations.

### Incorporate Group Activities

To draw fathers in and increase their initial involvement, programs should demonstrate the “how-tos” of creating fun activities for the whole family. Most men prefer whole family or

group activities rather than those designed singularly for fatherhood support. Vicki Turbiville's research in 1996 concluded that family-centered events and activities are highly desired by fathers of CYSHCN.<sup>8</sup>

It is ideal for fatherhood programs to provide hands-on demonstrations, tips and organizing techniques for putting together family-centered events. A noticeable rise in fathers' planning skills and confidence will occur as they easily meet their goal of delivering a few fun-filled hours to their families. They will take pride in repeating this success again and again.

Greg Schell, Director of the Fathers' Network, Kindering Center, Bellevue, Washington, says, "A successful strategy for encouraging father-child relationships is 'kid-dad activities.' Dads love events where they can attend a ball game or fishing event with their child or children." Schell has found that dads enjoy activities with their own children while mingling with other dads and their children.

### **Philosophies and Observations**

In multiple aspects of life - families, friendships, careers - humans experience a driving need for improved communication outcomes and results. Fathers often ask program leaders how they can improve communication with their children, wives, children's mothers and family members. *Fatherhood curriculums or Healthy Marriage curriculums such as PREP © [www.prepinc.com/](http://www.prepinc.com/) Couples Communication © <http://www.couplecommunication.com/> curriculums that implement a coaching style* vehicles for demonstrating non-threatening communication skills see impressive results.

In a safe, friendly environment fathers may be more willing to express their emotions and dialogue about care and provisions for their children and youth with special health care needs

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<sup>8</sup> Turbiville, V.P., (2001).

(CYSHCN). Miscommunication can shake the most stable of mother/father relationships; however, learning techniques respectful of both points of view is a definitive plus when achieving consensus is desired. Helping fathers improve their communication skills will positively affect their coping skills which may aid them when dealing with feelings of loneliness and isolation, anxiety and strained marital relationships.

### Increase Affirmations for Fathers

Mothers and children are the prominent focus of professionals supporting families with children with special needs which often causes fathers to be over-looked. And, as was implied earlier, males often shy away from accolades as they play the societal role of fixer/problem-solver. However, given an opening, fathers confirm that they, too, need affirmations for the vital role they play in their child's life. It is recommended that fatherhood practitioners and formal programs create a reoccurring agenda item for dads' praise and affirmation, one-on-one, as well as, from group members.

When society fails to verify that dads count, men fail to count in the lives of their children; therefore, it is vital that society reinforces responsible fatherhood in all social and moral codes. Often neglected and under-served, we laud this fatherhood population for resilience, perseverance and benevolence toward children and youth with special health care needs. It is the hope of this author that this paper feeds the flame of empowerment for individuals serving, leading and volunteering with fathers.

### **21 Practical Steps to Implement**

The next section of this paper presents practical steps and recommendations for enhancing practitioners outcomes and curriculum contents designed for fathers of CYSHCN.

Congratulations to programs that already have these as permanent fixtures, and for those ready to initiate change, you will be pleased at the ease of installation and quick results.

### Inclusive Programming

1. Set up social occasions for men to gather, converse and exchange ideas, as well as, promoting father-child involvement. This diminishes some of the isolation felt by men and provides a non-threatening environment for developing personal support networks.
2. Ensure that assessment records and care plans are written in a manner that is respectful of both parents and that the names of both fathers and mothers are prominent on all printed materials, mailings and emails. In the instance that the father is not present for document signing, confirm that all pertinent documents, care plans, permissions to treat or participate in services are specifically sent to him.
3. At the initial meeting discuss provisions for sharing information with the parent accompanying the child to services. When the custodial parent has given permission to share information and the father does not live with the mother and child, practitioners should take steps to send information and materials directly to the father's home, as well as, where the child is living. If parents have joint custody of the child, information can and should be shared without obtaining extra permissions.
4. Typically, when men receive information about "programs for parents," they immediately define them as mother-centered programs. A prime example is local PTAs (Parent Teacher Association). When asked about PTA programs, men will respond, "That group is for women." Underserved populations do not assume inclusion; therefore, fathers must first be told that there is a definitive place for them in your organization. Just as strides have been made to serve English-as-a-second-language populations, also underserved,

concentrated efforts must be made to amalgamate fathers. One way to promote inclusion is to substitute the word “parents” for “fathers and mothers” in all printed materials because many fathers associate the term “parents” with exclusively mother-centered programs. This purposeful inclusion will also serve to elevate the role of fathers.

5. Many fathers are hourly or shift workers with strict time schedules; therefore, accommodations should be made to flex meetings and counseling times. Introduce options for after-hours appointments to increase attendance and avoid work schedule conflicts.
6. In addition to offering flexible appointment times, consider video-taping physical, occupational or speech therapy sessions so that fathers can receive and experience the same information and strategies provided to mothers enabling both parents to productively support their child’s development. Other technologies, such as Skype, may be viable in some instances.
7. Program offices should be set-up as father-friendly environments with posters and displays portraying father-child enjoyment and interaction sending a clear message to men that “they are welcome in this place.”
8. Initiate father focus groups to evaluate programming and printed materials, as well as, to and recommend appropriateness of materials.
9. Include referral resources and materials specifically compiled to help dads with personal development, parenting and family life in general. (See NFI <http://store.fatherhood.org/> )
10. Train practitioners in methods and techniques designed to decrease the profound sense of loneliness felt by many fathers which can manifest in anger and negative responses. Practitioners who are prepared won’t be frightened by male anger or negativity.

11. Design program newsletters or other materials to include columns or articles specifically aimed at and written by fathers and other men. Ask the men to use active, engaging language written on an easy-to-read-level. Arrange for assistance by volunteers or staff for men who want to contribute but who feel insecure about their writing skills.
12. Value the men being served and express often the importance of what they provide to their children. Many men who are heads of households feel undervalued when financial provision is ranked secondary to nurturing and income size is the exclusive measurement for how well they provide for their families. Equal portions of nurturing and financial provisions are needed for family stability and success. Stay-at-home dads often feel undervalued for decisions and sacrifices they have made for their families. The special environments of fatherhood programs are ideal for helping clients keep their integrity and feelings of maleness intact and appreciated.
13. Practitioners and program leaders must be willing to work with (or through) mothers to involve fathers in their children's lives even when parent relationships are strained.
14. Design programming to build fathers' skills in effective communication, conflict resolution and successful partnering for parenting.
15. Task-oriented programming seems to be well received and aligns with men's activity-based learning preferences. Offer workshops on specific issues, such as, financial planning, wills, trusts, long-term planning, special needs, advocacy and strategies for policy change targeted to improve outcomes for CYSHCN.
16. All materials should be developed in a clear and concise manner with sensitivity to variations in audience literacy levels. Distribute information when appropriate and most useful.

17. Family events that include kid-dad-activities or promote healthy child-father relationships are strongly encouraged.
18. Fathers need a safe place and/or person to turn to for information related to their children. Strive to reduce the mother's role as the father's educator.
19. To further expand principles of fatherhood programs practitioners are urged to strongly promote parent-to-parent support and relationship development between new parents and veteran, trained parents. When possible match parents who have children with similar disabilities, needs or preferences. For a listing of Parent to Parent organization see: <http://www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx> . For the Family Voices chapter in your state go to: <http://www.familyvoices.org/states> .
20. Make it a high priority to assign male staff, or staff who are also fathers of CYSHCN to deliver service for male participants.
21. All staff members should have the understanding that programs are designed for both mothers and fathers and that the responsibility for engaging, inviting, empowering and affirming fathers is jointly shared by all staff. During meetings staff should commit to equal levels of interaction with mothers and fathers.

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