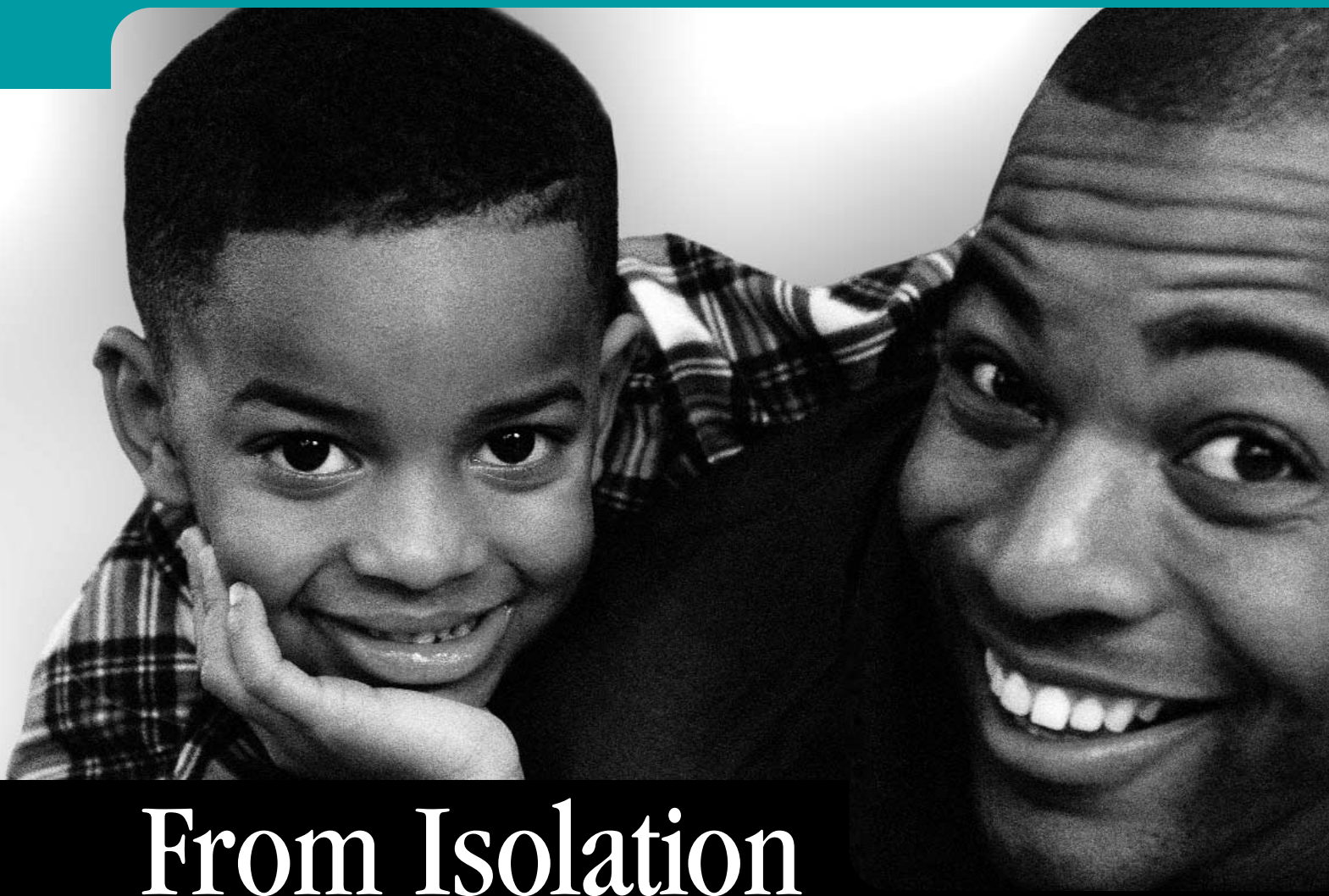

From Isolation to Transformation:

A CARE Act Guide to Supporting Men Caring for Children Living with HIV/AIDS

AIDS Alliance for Children, Youth & Families

Through education, training and advocacy, AIDS Alliance for Children, Youth & Families addresses the needs of children, youth and families living with, affected by, or at risk for HIV and AIDS.

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by James May & Ronnie Nanton

Acknowledgements

Writing this monograph has been a privilege. My awareness of the complex issues facing male caregivers has been challenged and enhanced throughout this ambitious undertaking. It is abundantly clear that we have an opportunity to change the face of health care delivery in this country and become truly family-centered — in theory and outcome.

This project would not have happened without the assistance of many friends and colleagues. Ronnie Nanton of Miami, extraordinary friend, undaunted advocate for men and their families, and superb father to his son, Darrious, gave his time and energy with generosity and care. My thanks go to Jacqueline Coleman and David Harvey at AIDS Alliance for Children, Youth & Families for their support and belief in male caregivers and in this work.

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Eddie Rodriguez, you always taught me to laugh, even in the midst of the pain. Rest in peace, my friend.

— James May

Chapter One | Overview

> He is a tall man, with a brisk stride. Tightly gripping the hand of his son, he enters the clinic. His demeanor is serious, rather tense. Amidst the din of children playing, he duly notes that he is the only male in the waiting room — a familiar scene. A few faces are recognizable, but little conversation is exchanged. He has come to the clinic as a father, a caregiver, and an advocate for his child's medical needs. His ability to succeed will be determined by a variety of factors out of his control.

In countless clinics and agencies throughout the U.S., such scenes take place each day. Male caregivers raising children with HIV face needless barriers that create isolation, stress, and discouragement. By examining and removing these barriers, health care providers and consumer advocates can transform the care delivery system, opening it up for active involvement by fathers.* Fathers' engagement can result in improved health for children and increased confidence for fathers — the two go hand in hand.

Fathers caring for children with HIV are paramount — irreplaceable — to their children's health outcomes. A single dad explains, "Without my care, he won't get to the clinic, he won't take his drugs or eat properly, and he will die. It's all up to me." Another man says, "I have to learn about all the different medications he takes and deal with all the side effects.... These drugs are very powerful and knock him for a loop a lot of times. It's a major challenge for me as his dad, constantly watching him and making sure that he's doing okay. I experience a lot of fear because of this." A National Cancer Institute study acknowledges these experiences: "Fathers caring for children living with HIV/AIDS experience heightened psychological distress and suffer from stress in their parenting roles" (Wiener, Vasquez, & Battles, 2000, p.7).

From Isolation to Transformation: A CARE Act Guide to Supporting Men Caring for Children Living with HIV/AIDS is a resource for care providers and advocates who recognize the difficulties these men face in the health care system and want to do something about it. It is a guide to advocating and developing support services for fathers and other men caring for children and youth living with HIV and AIDS.

Using This Guide

From Isolation to Transformation is intended for CARE Act administrators, service providers, and male caregivers who want to start, expand, or improve services for men who are caring for children and youth with HIV disease. The guide offers a research-based rationale for such services, something consumers and providers who have developed programs for men say is essential in this era of competition for scarce resources.

Readers familiar with the value of support programs for men and the research underpinning such services may choose to skip ahead to Chapter Six, "Tips and Tools for Effective Programs for Men." For readers wishing to learn more, Appendix B provides a comprehensive annotated list of books, as well as a list of organizations and other resources.

> Developmental research clearly shows that children are born with a drive to find and connect to their fathers, and fathers have the internal capacity, the instinct, to respond. Children and fathers hunger for each other early, often, and for a very long time.
>
> —Kyle Pruett (2000)

*** The term "father" is used throughout to mean any man who plays an important role in a child's life — biological fathers, step- and adoptive fathers, or father figures, including extended family members such as grandfathers and uncles, and friends.**

Chapter Overview

Chapter Two, "The Benefits of Male Involvement with Children," reviews recent changes in fathers' roles and examines the risks to children when fathers or father figures are not involved in their children's lives and the benefits when they are involved. The value of support programs for men raising children with HIV disease is described in the words of the men themselves.

Chapter Three, "Pushing Past the Stereotypes," examines the effect of stereotypes on these men and their relationships with health care providers. The importance of examining one's own expectations and beliefs about father involvement is stressed, and a checklist is offered to help providers do so.

Chapter Four, "Cutting Through the Isolation," looks at factors that tend to isolate men caring for children with HIV disease, including cultural influences and emotional responses. Support programs for these fathers are suggested as part of a family-centered approach to changing the health care system.

Chapter Five, "Barriers to Male Involvement," outlines common barriers that can interfere with the ability of fathers to raise children living with HIV disease and get them what they need from the health care system.

Chapter Six, "Tips and Tools for Effective Programs for Men," offers strategies and tools for conceptualizing, establishing, maintaining, and evaluating support programs for fathers caring for children with HIV and AIDS.

Chapter Seven, "Program Models for Supporting Men," describes three different approaches to support programs for men: Men on Board in Miami, Florida, Project Brotherhood in Chicago, and Men's Educational Needs and Services in metropolitan New York.

Chapter Eight, "Final Thoughts —Transformation and New Understanding," summarizes the guide by considering support for caregiving fathers as a vital part of family-centered care. The health care delivery system is challenged to respect and support the value of men in the lives of children living with HIV and AIDS.

In Their Own Words

Both male caregivers and health care providers contributed to this guide by sharing their thoughts and experiences. The candid — and sometimes provocative — comments of the many men who participated appear as sidebars throughout the guide. They demonstrate the powerful, unconditional love they have for their children and illustrate the often lonely journey that men travel when they are primary caregivers for children living with HIV and AIDS.

> **I want to do a good job. You know, she's my kid and I love her more than anyone in the world. When she passes, I want to be able to say I did everything I could for her. And that's what I intend to do.**

The providers who generously gave their time and energy to this project all agree that the issues in the guide are long overdue for discussion, understanding, and change. They know that family-centered care means respect and support for all people who care for and treasure children — men as well as women.

Chapter Two | The Benefits of Male Involvement with Children

> It is undisputed among researchers and policy pundits alike that fathers' involvement is extremely important for children's proper social and emotional development. Furthermore, fathers interact differently with their children than do mothers, and it is fathers' unique interaction that is said to help specifically children's emotional development. (U.S. Census Bureau, 1997)

In the past three decades, a man's relationship to his family, children, and employment has changed dramatically. Men's priorities are evolving, and increasing numbers are as concerned about having healthy emotional relationships with their children as they are about being good breadwinners. Despite these changes, the United States has the highest rate of absentee fathers in the world. Estimates are that half of all children today will grow up with the daily presence of fathers; half will not.

No one questions whether children need mothers, but even today some administrators and care providers question the importance of fathers and father figures in children's lives. Others question the need for male-focused services. This chapter summarizes the research on the benefits of male involvement and the value of support programs for male caregivers.

Children at Risk

There is increasing evidence that children are placed at risk when fathers — or father figures — are not involved in their lives. A variety of current studies are consistent in their findings:

- Children are at risk for increased economic hardship. Children in father-absent families are five times more likely to be poor and 10 times more likely to be very poor than children in father-present families.
- Kyle Pruett (2000) writes that children yearn deeply for dads, and children growing up without a father experience profound feelings of loss.
- Children are at risk for behavior problems, poor academic outcomes, emotional problems and poor self-esteem, social difficulties, and drug and alcohol abuse if raised without a father or strong male figure.
- Young males are more likely to be involved in criminal activity or be incarcerated if raised without a father or strong male figure.

Research shows that father involvement enhances children's social development.

The Value of Father Involvement

Research by Kyle Pruett, Michael Lamb, David Popenoe, Ross Parke, and others clearly shows that strong father involvement yields powerful, positive results:

- Father involvement enhances children's capacity for independence and risk-taking and helps them develop a positive view of their future.
- Boys with strong relationships with fathers or father figures develop more empathy and sensitivity towards others and learn how to control their aggressive impulses.
- Girls with strong relationships with fathers or father figures are more able to develop healthy, appropriate relationships with the opposite sex.

Male Caregivers

Two million fathers in the United States are single parents, a 50 percent increase since 1990; 3.1 million children live with their father only, triple the number in 1980 (U.S. Census Bureau, 2000). Among the 6.3 million married-couple families with preschoolers where the mother works, 25 percent of the fathers care for the children during the mothers' working hours (U.S. Census Bureau, 1997).

I just don't know where I'd be without this support group. They've opened up so many doors for me. I remember the first time I came with my son and not knowing what to expect. Here I am sitting on a chair in a circle with five or six men sharing my experiences and problems. It sounds so simple, but what a powerful effect it has. As I'm leaving the group that evening I get the feeling that I'm closer to my child than I have ever been since he was born, but I didn't actually spend much time with him. Wow!

Howard Dubowitz, director of the University of Maryland's Child Protection Program in Baltimore, studied the impact of a supportive father figure on 855 young children considered at high risk. He concludes that dads make a big difference: children with active male involvement lead richer lives, are more confident, and learn better than similar children who lack a father figure (Dubowitz, 2000). The U.S. Department of Education also reports that when fathers are highly involved in their children's schools, children are more likely to enjoy and do well in school, and are less likely to have ever been suspended or expelled (NCES, 1998b).

Until I came to the first men's meeting, I never knew other guys felt the way I did. It was amazing to hear guys talking about their stresses and fatigue. I actually thought they were talking about me. I've come to realize I'm not alone, that there's a lot of people out there with a lot worse than HIV. I don't feel like an outcast any more, like I have the plague or something. I can come and just talk and relax.

Benefits of Father Support Programs

Little research to date has focused on the benefits of father support programs in health care environments. Even in early childhood settings, where much of the research has taken place, findings have been limited by small sample size or by a lack of control and experimental groups.

Two early studies, though, shed light on potential outcomes. Markowitz (1984) demonstrated that fathers involved in support groups communicate better with their families, experience less stress and tension, are more willing to share the responsibilities of caring for their children, and better accept their children's disabilities. Also studying support programs for fathers of children with disabilities, Frey, Fewell, Greenberg, and Vadasy (1989) found that both men and their partners experience improved self-esteem and fewer feelings of failure, as well as less stress, tension, depression, and fatigue.

Men raising children living with HIV and AIDS say that support programs help them:

- clarify their medical and personal needs and the resources they need to help their children;
- increase their parenting skills and their ability to nurture their children;

- strengthen their ability to cope with the unique challenges and stresses of raising a child with HIV and to openly discuss grief and loss, as well as happier times;
- know what resources are available for their children and how to get them; and
- learn advocacy skills and understand their legal and personal rights for their children and themselves.

Meeting other men raising kids with HIV has changed my life for the better. I've learned so much from being around these guys. I've never had a chance to talk about depression or sadness before. Here that's okay. I've learned a great deal about new medical treatments. I've also learned to be nicer to myself. Before this group nobody could kick my butt worse than I could. I was definitely my own worst enemy. Now I've lightened up. I think we've all learned that we're darn good dads.

Chapter Three | Pushing Past the Stereotypes

> Labels that health care professionals put on families can be very detrimental.... Fathers of color who are assertive, who demand to be treated in a respectful way ... and go after what they believe is the appropriate level of services for their children unfortunately are sometimes labeled "hostile."
>
> — Herman Gray, M.D.

Stereotypes inhibit understanding, tolerance, acceptance, and generosity of spirit. Yet, men are frequently stereotyped, especially in the media. Watching television, one might conclude that most men are hard-drinking womanizers, unable to cook or clean, let alone care for children. Especially in commercials, men exhibit little sensitivity or concern for anything other than sports, work, or owning hot cars and grown-up toys. Too often, they are portrayed as buffoons and eternal adolescents.

Although this societal stereotype is changing, it is still evidenced in many health care settings where men are viewed as having limited parenting skills, knowing little about medical issues, and being difficult to deal with (King, King, & Rosenbaum, 1996). Add HIV to this equation, and issues like drug addiction, abuse, unemployment, and incarceration may come to the forefront. This chapter considers how to recognize and move beyond these harmful stereotypes.

Identifying Expectations, Biases, and Beliefs

A common theme among the fathers and care providers interviewed for this guide is that men have to prove themselves in a system that judges them to be incompetent parents. They hear a clear message: you will be held to a higher standard, and you must show us you are equipped to take care of your child. One man offers, "It's as if I'm already judged before I enter the door, and this creates a stress." A provider agrees:

> There is a bias against these men by the virtue of the fact that they're men. There are so many stereotypical, unattractive images regarding who they are. The father may be affected as a result of drug use or promiscuity, may have once been in jail. Why is he not working? What does he know about rearing children?

Advocates for programs for men encounter the same stereotypes, time and time again: men cannot nurture children as well as women can; men are not interested in being part of their children's health care; men cannot be trusted as primary caregivers. Far too many people think of fathers and other men as appendages to mothers — someone to drive mothers and children to the clinic, pay the parking, sign some forms, and then return them home.

> **I generally go to the clinic with my wife. But I remember the day I went alone. The very first question I was asked was, "Where's your wife?" I knew what they were getting at — that she was the expert and that I didn't really know much about the care of my child. That's really patronizing, you know.**

Such stereotypes actively inhibit father involvement. In fact, a study of Head Start programs (Levine, 1993) found that the ambivalence of staff was one of two key factors limiting male involvement (inappropriate program design and delivery was the other). Values and attitudes determine program design and outcomes, as well as the policy that drives them. All of us — providers and family — must explore our values and understand how they affect our interactions. Examining our biases and belief systems also can help providers identify and remove roadblocks to active male participation. Table 1 offers a list of questions about male involvement that providers may find useful in examining their perspectives.

Table 1

Beliefs About Father Involvement: Questions to Consider

- What beliefs do you have about the contributions men make to children and their development?

_____
_____
_____

- What is your goal in involving men? What do you hope to achieve by involving men?

_____
_____
_____

- What would your program be like if you met your goals of involving more men?

_____
_____
_____

- What would your program be like if as many men participated as women?

_____
_____
_____

- In what ways do you hope to involve men? In what capacities? With what frequency?

_____
_____
_____

- In what ways do fathers and other men want to be involved? How can you find out?

_____
_____
_____

- What will you have to do to involve men that is different from involving women?

_____
_____
_____

- How can your program communicate with men directly rather than through mothers?

  _____
  _____
  _____

- Are all staff equally comfortable about involving fathers and other men? Are you comfortable with all men or only some kinds of men? Which men? Why?

  _____
  _____
  _____

- How will you handle resistance from staff and other parents who are uncomfortable working with men, who feel some men are the cause of family problems, or who feel that resources are better spent on women and children?

  _____
  _____
  _____

- How will you rethink parent involvement to include a specific focus on men that doesn't dilute what you offer other parents or mothers? How will you do this in a way that does not give staff additional and burdensome responsibilities?

  _____
  _____
  _____

- How will you commit to male involvement in the long term rather than addressing it as a one-time issue or as a special event or day, because it is currently a "hot" topic?

  _____
  _____
  _____

Source: Team Attending PSESDFII (1999)

Chapter Four | Cutting Through the Isolation

> Good fathering flows from the realization that being a father is important, vital, demanding, rewarding, and risky. Telling your story of what it is like to be your father's son and your child's father to another father and another, and listening to their stories in return is ultimately the only school for fathering.
>
> — L. Streiker

Because the vast majority of children living with HIV have been infected by mother-to-child transmission, many will lose their mothers to AIDS. Some will be raised by grandparents and other extended family members. Many will be raised by their fathers or other male caregivers. Despite their numbers in some communities, men caring for children living with HIV often are profoundly isolated. They often have limited support systems and may choose to live in silence rather than risk telling someone the truth about their circumstances or their feelings. This is particularly true of men who are living with HIV themselves:

> Yeah, I tell you I was very alone. Before I just thought I was in this by myself.... I didn't want to talk to nobody about this. I didn't even want to accept this myself. I denied ever having HIV. If somebody asked me I would say "no" and the same for my child. The only people that knew was the nursery and my mom, and that was it.

This chapter examines some of the factors that tend to isolate men caring for children with HIV disease and recommends male support programs as part of the answer.

> **I have a lot of guilt. He shouldn't have been born with this. He doesn't deserve to have this awful disease. I feel like it's my fault, and that's why I do everything I possibly can to make sure he's all right. Anything I can do. It hurts, especially when I know he should have been born okay. I have so many regrets, so much guilt.**

> **I tell you, it's always a constant fear. I mean I can't escape the fact that it bothers me in one way or another. When I hear of a parent's loss, it just puts all types of unwanted expectations in my head, that I may have to go through that with my child also.**

Isolating Factors

The reasons for this isolation are complex. A father raising a child with HIV alone often passionately protects his child, hoping to avoid potential discrimination in housing and work, maintain family privacy, avoid legal disputes, and maintain a normal life. The limited research on fathers of children with special health care needs suggests other reasons for this isolation, including that men may stay in denial longer than mothers before accepting the truth about their children's chronic health condition (Tallman, 1965); another response may be resignation (Mallow & Bechtel, 1999).

> **I am now ready to get on board and be a real father for this child. I can't deny my responsibility any longer.**

Conditioning and Cultural Influences

Many men are shaped by cultural influences that view men as strong, competitive, in charge, and able to go it alone. Robert Bly, Sam Keen, and Herb Goldberg write extensively about men viewing vulnerability as a weakness. This mystique makes itself evident when men must demonstrate that they:

- don't need strong connections to family or community;
- don't tire as easily as women and can tolerate high levels of pain;
- are unemotional, rational, competitive, and like to be in control; and
- are proficient and almost machine-like in their work.

> **I'm one of those who don't talk. I just believe that you keep your personal problems to yourself. You don't put them on other people. You pay your own bills, you take care of yourself, and that's it. That's the way life works. You don't ask nobody for nothing.**

Being a rugged tough guy, the John Wayne mentality, is often a strongly held ideal, revered for its machismo. The Vince Lombardi credo — "Winning isn't everything; it's the only thing" — lives on.

Although certainly changing in their roles as fathers, men often still define themselves in terms of these projected cultural images. Males may value being in control, taking charge, and being competitive, and they may place a high premium on rationality and analytical thinking. They also may be task oriented and endure stress as a badge of honor rather than call for help. Such self-imposed expectations and reluctance to seek help are evident in health care utilization figures: men are two and one half times less likely than women to seek preventive care (National Center for Health Statistics (NCHS), 1998). Mental health counseling may be viewed as a "feminine" activity, and untreated clinical depression may mask itself in aggressive, confrontational actions. Men also die on average six years earlier than women, and men from non-dominant cultures, particularly African Americans and Hispanics, die earlier than do white men (NCHS, 1998).

Emotions Rising to the Surface

Many emotions commonly experienced by men caring for children with HIV and AIDS can also be isolating. Few studies have focused on fathers parenting children with HIV, but anecdotal evidence is convincing that men experience guilt, depression, and ongoing fear. In a National Cancer Institute (NCI) study of 31 fathers of children ages six to 19 — "Fathering a Child with HIV/AIDS: Psychosocial Adjustment and Parenting Stress" — Wiener and her colleagues (2000) found that more than 50 percent of the men experience significantly more parenting stress and psychological distress compared to fathers of children without HIV.

The complex and sometimes overwhelming decisions fathers face also can contribute to isolating emotions: "What medical treatments are best? Who will I disclose to, and what will they say? What consequences could we face?" If the man also has HIV, another layer of issues is added: "Will I stay well enough to care for my child? If I have to go to the hospital, who will take over for me? Will they know what they are doing?"

Some men may isolate themselves rather than risk public expression of emotions. A man who is unemployed, for example, may be experiencing humiliation and guilt over his inability to provide for his family. Such shame is likely to produce embarrassment, confusion, and discomfort.

> **Sometimes it gets really depressing, especially when I had to arrange ahead of time for when the moment comes that I die — preparing a health care plan, a living will, and all that stuff.**

A Family-Centered Approach

Services that support men are also powerful supports for their children. At the heart of family-centered, culturally competent care for children and youth living with HIV and AIDS is recognizing the strengths and resources present in all families and supporting all family members, including fathers and other male caregivers.

Noted sociologist John McAdoo (1993) observes:

> Fathers exist as part of the family system, and should not be viewed in isolation. They should not be seen

> as separate from their families or from their communities. Human services decisions made about fathers should consider the connections between these individuals and the social ecological system in which they live (p.2).

A child with HIV presents complex medical concerns that test even the most family-friendly environment. If the father is single, systems of care need to go the extra mile — as they must for single mothers — attending to concerns such as care for other children, flexible appointments, and easy pharmacy access, as well as unexpected hospitalizations.

The good news is that men will identify support needs when they are given the right opportunity: 97 percent of the men in the NCI study say that they would be helped by men's support groups, as well as by help with discipline, disease management, and planning for the future. Programs for fathers can erase the isolation these men often feel and help them build a support system that empowers them as advocates for their children in clinical settings. This is family-centered care — in theory and outcome.

Chapter Five | Barriers to Male Involvement

> I consider myself an intelligent, reasonable person, a rational person, a polite person. None of these qualities helped much in my initial dealings with the health care system. Initially I was treated like a bystander. Once when I asked a question the answer was given to my partner. I experienced much anger. I felt like the invisible man but worse because I was not invisible but ignored.

Fathers may encounter a variety of barriers finding and using health care for their children living with HIV and AIDS. The hierarchy and cumbersome bureaucracy of the health care system are often intimidating. Institutions may not reinforce the message that preventive care and continuity of care are crucial to a child's health. Language differences and cultural beliefs may profoundly influence outcomes. For some men the end result is fear and hopelessness, made evident in a lack of trust, aggression or passivity, and lowered self-esteem.

This chapter outlines common barriers men may face in their interactions with the health care system on behalf of their children living with HIV disease. They include limited research, inflexible scheduling, a care delivery system that focuses on mothers and is dominated at the service delivery level by women, gatekeeping, male responses to grief and loss, a lack of social supports, negative experiences with the health care system, and bias in legislation and public policy.

Limited Research

> Until recently, fathers were the hidden parent in research on children's well-being. Their importance to children's financial well-being was widely accepted, but their contribution to other aspects of children's development was often assumed to be secondary and was not usually examined. (NCES, 1998a, p.1)

Until the late 1960s, research was based on "father absence" rather than "father presence," and data was collected primarily by interviewing mothers. As late as 1983, Wolf Wolfensberger observed, "Much of the research leaves one wondering whether handicapped children have fathers" (p.9). Sabbeth (1984) concludes that fathers "have been relatively excluded from the research, as they have been from many pediatrician-mother-child interactions" (p.47).

Little has changed today. A notable exception is the work of Dr. Lori Wiener of the National Institutes of Health. She has been instrumental in examining the roles and concerns of fathers of children with HIV. Additionally, Dr. David Strug of the Wurzweiler School of Social Work, Yeshiva University, has conducted an exploratory needs assessment of the support needs of men caring for HIV-infected and affected children.

Inflexible Scheduling

Rigid scheduling in hospitals and clinics can deter father involvement. Men often do not have the work flexibility to participate in 9:00 to 5:00 appointments, and some fathers also encounter a double standard at work that says it's all right for a mother to stay home with a sick child, but not a father. Early morning, late afternoon, and weekend appointments help remedy this situation.

Services Focused on Mothers

Traditionally, health care providers have focused services on mothers when children have a chronic illness, and fathers can tell. In a study of 128 couples, King and Rosenbaum (1996) note one significant difference in the experiences of mothers and fathers: fathers believe that providers think they are not interested in their children's care. Many health care settings do, in fact, continue to reflect this bias.

One provider describes barriers that limit male involvement, "Many fathers do work, and they can't easily bring the children into the clinic themselves. From the kinds of pictures on the wall to the literature provided, it's clear that it's mother and child health. It rarely has a father-friendly atmosphere."

Gatekeeping

Many men, for lack of role models or conditioning, fear making mistakes or not having the knowledge to make the right choices for their children. Women can open or shut the door to much of this learning. Lillie (1993) calls this "gatekeeping." Gatekeeping interferes with active, ongoing male involvement in children's care by limiting men's opportunities to develop the confidence and expertise they need to take care of their children. It is a Catch-22, especially when mothers' illness or death results in fathers becoming primary care providers without the necessary resources and information about their children's health history, medications, treatment regimens, and schooling.

Male Responses to Grief and Loss

For many men, anger is a traditional emotional reaction to loss. Underneath the anger is sadness, fear, and a feeling that life is out of control. Such angry responses are typically misunderstood. One nurse says she told a father, "I took your lack of smiling and curt tone of voice as a statement that you were unhappy with me. It has taken me a long time to realize that this is not the case. You were simply scared about your child's health." Men often have learned not to show feelings, particularly feelings of sadness, loneliness, and discouragement, choosing instead to suffer in silence. A grief counselor warns that a father may "carry his grief as a solitary burden in his head and his heart for years. It doesn't have to be that way" (Staudacher, 1991).

Lack of Social Supports

Research is clear that there are fewer systems of emotional support for men who are raising children with special health care needs than there are for women. Only one national program, the National Fathers Network, has received ongoing federal funding to address such concerns and develop supports for male caregivers. This lack of personal and social support may result in high levels of stress, depression, and isolation that discourage men from participating in programs for their children (Ferrari,1986).

Men in a Realm of Women Providers

The majority of health care providers are women, which causes some men to feel ill at ease and guarded, and there may also be issues of male/female boundaries. Women providers who have experienced negative relationships with men may find it difficult to be at ease with males or to create an atmosphere built on trust. The same may be true of men who have experienced negative associations with women.

> **Every time I take my child to doctor appointments, there's all women in there. It's a great thing that I have a male case manager. For me, it's a lot easier to talk to a man than a woman. I feel more comfortable, especially talking about personal problems or male problems that I go through with my son.**

Negative Experiences with the Health Care System

In some communities, a history of racism and mistreatment in the health care system contributes to isolation. Such tragic events as the Tuskegee experiment, in which African-American men were lied to about their illness while their syphilis was left untreated, contribute to a widely held belief that health care providers cannot be trusted.

Bias in Legislation and Public Policy

> Reflecting the bias in research on child development, many federal agencies and programs dealing with family issues focused almost exclusively on mothers and their children. (NCES, 1998a)

Title IV of the Ryan White CARE Act has been central to the creation of family-centered, culturally competent care for children with HIV and their families. Title IV grew out of maternal/child health programs, and, in general, the language of Title IV initiatives and requests for proposals reflects this emphasis on mothers and children. Unfortunately, this lack of male visibility may reinforce fathers as not integral to their children's care.

Chapter Six | Tips and Tools for Effective Programs for Men

This chapter offers strategies and tools for developing and operating support programs for fathers caring for children living with HIV and AIDS. They are based on both research and the experiences of health care providers and consumers who have established and run support programs for men.

Fatherhood Initiatives

The paucity of research on male involvement in health care settings — particularly on fathers raising children with HIV — means that providers must look to other sources for information. Head Start and early childhood programs have been at the forefront of developing male participation, and their findings offer insight on building effective partnerships with men. McBride, Obuchowski, and Rane (1996) conclude the following about fatherhood initiatives:

- Be specific about goals. Know and understand why such initiatives for men are to be developed and how they fit the overall philosophy of the organization.
- Acknowledge resistance to initiatives. Help people understand that male involvement is important to family-centered care, and know that some people will resist such change for personal and financial reasons.
- Identify the significant male role figures in a child's life. Focusing on biological fathers will exclude a large proportion of men who play significant roles in children's lives.
- Provide training and support services for staff. Staff will need to believe in and accept the value of father involvement, and in-service training can be invaluable in helping staff embrace males as part of care delivery.
- Encourage female staff to support male involvement. While male leadership is advantageous, it is not always possible to staff such programs with men only.
- Provide information about the differences males bring to parenting so that staff will have the impetus and knowledge to build effective relationships.
- Don't neglect mothers. Male involvement must not be developed at the expense of mothers and mother/child initiatives. Encouraging women to be part of the leadership teams for male involvement will add depth of understanding and further the chances for success.
- Don't reinvent the wheel. Programs for men should be integrated into existing family support programs. Evaluate what already exists and explore how it can be adapted to reach fathers.
- Go slowly. Men will not necessarily embrace these programs with ease. The number of participants should not be the sole indicator for success. With time, energy, and effective leadership, men will participate and realize they are welcome — and expected — to be part of their children's care.

Core Strategies for Father-Friendly Support Programs

> Going to the fathers' group was difficult at first, but now it has become very comfortable. I really like talking with the other guys, meeting their kids, learning how they are doing. I can ask questions here that I might not ask in other places. We laugh a lot, and that feels great.

For 15 years, with funding from a federal Maternal and Child Health SPRANS (Special Projects of Regional and National Significance) grant, the National Fathers Network (NFN) developed support programs and curriculum to enrich the lives of fathers of children with special health care needs, including those with HIV/AIDS. In developing more than 100 support groups throughout the United States, the NFN identified key strategies for building powerful, successful support programs. Table 2 lists these core strategies.

When creating programs for men, think outside the box. Men will participate if offerings are relevant to their needs and combine learning and personal support.

From a Provider's Perspective

Just as there is almost universal agreement among the fathers interviewed for this guide, the providers participating also agree about the pressing need for father support programs and approaches likely to be successful. Waldo Johnson, a professor and researcher at the University of Chicago, suggests the following:

- De-mystify the health care system and what health care providers do. This is especially important with men who have been outside the health care system in terms of access to care for themselves.

- Think broadly about the roles of mothers and fathers and about the benefits to children of having more than one primary caregiver when it comes to interactions with the health care system. Children living with HIV disease, who often have at least one sick parent, will have better continuity of care when both mothers and fathers are supported as caregivers.

Table 2

Core Strategies for Building Father Support Programs: A Checklist

- **Encourage strong father leadership.**
  Use men to market, recruit, and facilitate. Models where men and providers share leadership have proven remarkably successful. Help the men learn the essentials of facilitating and group leadership, building group norms, handling differences of opinion, ensuring confidentiality, listening to each other, and sharing air time. Above all, let men learn from the other men. It is their program.

- **Build programs from within.**
  Ask men what would be helpful to them, and work collaboratively with them to meet their stated needs. Imposing ideas on them about what they must learn is likely to be rejected and viewed as patronizing. Respect the culture and backgrounds of the men involved, including age, ethnicity, socio-economic status, and geographic community (i.e., rural, inner city).

- **Create a place for men to share their feelings.**
  This may be especially true for anger and fear, feelings they may consider weaknesses. Many men have tuned out such feelings. Not wanting to lose control, many are anxious about being seen as burdens. Provide a supportive, safe, and trusting environment for men to share such personal concerns. Look beyond actions alone and see the messages men are sending out. Remember that what you see isn't necessarily what is really going on.

- **Build camaraderie through laughter and having fun.**
  Social times and activities — both with their families and for men only — provide necessary respite and ways

for men to build strong and lasting friendships. Having non-alcoholic beverages and food available creates an easygoing and relaxed atmosphere.

- **Make available printed materials on issues men say are important.**

  These might include health care, advocacy, education, medications, depression, anger management, etc. Make sure that materials are printed in a variety of languages and that interpreters are available if needed. Ask speakers to facilitate discussions on these topics.

- **Provide developmentally appropriate father/child activities.**

  Attend a ballgame, sponsor a picnic or barbecue, or visit a children's museum or petting zoo. Provide meals, transportation, child care, and other necessities whose absence can prevent many men from being able to participate. Use community resources whenever possible. Many programs make small toys and books readily available for men to take home at the end of meetings.

- **Feature comfortable settings and flexible schedules.**

  Find times and places where men are able to attend meetings, such as after work or weekends. Make sure meeting places are friendly, comfortable, non-clinical, and relaxed.

- **Create opportunities for men to celebrate and brag about their successes.**

  This takes time to establish, but it is ultimately invaluable. A father raising a child with HIV is surrounded by negatives and so often is reminded that the future is clouded by fear and anxiety. Celebrating successes is both fun and empowering.

- Affirm the right of men to be there. Many men feel that they must be demanding in order for their presence to be acknowledged. Openly affirming their right to be part of their children's care can help prevent difficulties and misunderstandings.

- Be the kind of provider who engages men and is open to their questions, even potentially challenging questions such as "Now, why should my child have to take this kind of medication?"

- Look for emotional as well as institutional barriers to male involvement and remove them once they are identified. Send messages that entice and welcome fathers and other men involved in the lives of children living with HIV disease.

Assessing Systems of Care

It is imperative that hospitals, clinics, and agencies look at how they deliver care and determine if they are father friendly. Table 3 lists questions that may be useful in assessing and developing programs for men raising children with HIV/AIDS and other special health care needs.

Table 3

Involving and Supporting Fathers: A Self-Assessment Checklist for Agencies and Providers

- ❑ Are there staff in-service programs on improving the quality of services for men raising children with HIV? Are men part of the training team?
- ❑ Are efforts made to have the father or a key male figure in attendance at intake interviews and other initial contacts with families?
- ❑ From the beginning of a program's contacts with families, are inquiries made about fathers or other important male figures in a child's life? Is it made clear that fathers or other male figures are important and necessary as part of the care team?
- ❑ Are men on staff as social workers, nurses, intake personnel, consumer advocates? Are men actively recruited and employed?
- ❑ Are fathers on the board and on standing committees where policy decisions are made?
- ❑ When telephoning families, do medical and social service staff ask for both the mother and the male caregiver, when one exists?
- ❑ If the mother is the custodial parent, is information regarding the child also mailed to the father (if approved and legally appropriate)?
- ❑ Are fathers or other male caregivers provided adequate notice of their children's upcoming appointments?
- ❑ Do staff encourage fathers and male caregivers to attend clinic appointments and other meetings by providing enough lead time?
- ❑ Are clinic appointments and other meetings scheduled at times conducive to fathers attending (i.e., early morning, lunch, late afternoon, Saturday mornings)?
- ❑ When a father or other male attends a clinic appointment with his wife or significant other, are resources and questions directed toward him? Are his contributions welcomed and openly valued?
- ❑ Do the program's newsletter or marketing materials reflect the concerns of men and the roles men play in their children's lives by including features such as a column written by a dad or an article aimed at male caregivers?
- ❑ Do printed materials and program spaces have pictures of men actively and positively engaged with their children?
- ❑ Does the program offer services and supports designed for men such as father panels, father/child social occasions, and programs of particular importance to males? Is child care made available for these events?
- ❑ Is there a father support program available within the clinic, agency, or program? Are families given information about such programs? Are women asked about possible male referrals to these programs?
- ❑ Are men raising children with HIV available as one-to-one mentors for discussion, information, and sharing? Are men on the clinic or program staff as family advisors or peer educators?
- ❑ Is there a quality resource library available — whether written, audio, video, or Internet — where a man can get access to information about the special medical, developmental, and emotional needs of his child? Is the information available in a variety of languages and formats?

Source: National Fathers Network

Chapter Seven | Program Models for Supporting Men

> There is no point in criticizing men for what hasn't happened or what should have happened. Let's support what can happen. Let's start with where we are at and see what we can do with what we have in front of us.
>
> — Ronnie Nanton

No one model is best for all men or for all environments. Across the country, a variety of models are being used successfully to support caregiving men and increase their participation in their children's health care. One program focuses primarily on social occasions, with men bringing their children to play while they discuss common challenges. Information is always available, and men are encouraged to ask questions and learn about available medical services. Other programs are more formal, providing speakers on topics men in the program identify as important, such as new treatments for children living with HIV, side effects of medications, continuity of care, and wills, guardianships, and other permanency planning.

Many programs include their offerings for men as part of a broad social service curriculum for families. The goal is collaboration and inclusion. The following programs illustrate both the diversity and commonality of programs for men caring for children with HIV disease.

This chapter describes three very different support programs for men raising children with HIV disease: Men on Board in Miami, Project Brotherhood in Chicago, and Men's Educational Needs and Services in metropolitan New York.

Men On Board

Men on Board (MOB) is part of the Miami Family Care Program, a Ryan White CARE Act Title IV program at the University of Miami School of Medicine, Departments of Pediatrics and Obstetrics and Gynecology. Through a multidisciplinary team of professional and consumer staff, the Family Care Program offers an array of services to men, women, and children affected by HIV/AIDS.

Ronnie Nanton, a peer educator with the program, was instrumental in starting Men on Board to provide a variety of support services to male caregivers. Based on his experience developing the Men on Board program, he offers tips about building ownership among men and helping a program grow and flourish (see Table 4).

For readers interested in a comprehensive history of Men on Board, Appendix A details how the program was developed, describes how it operates, and discusses plans for the future.

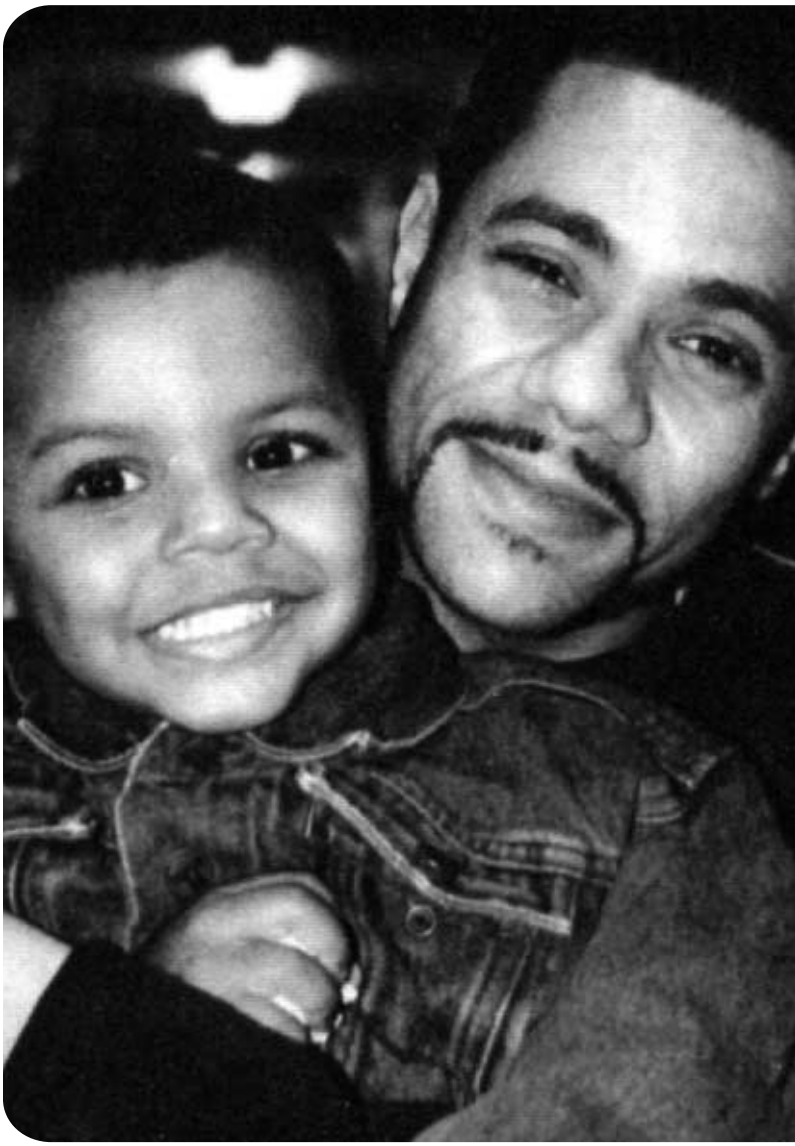

Table 4

Tips From the Frontline

❑ Develop an atmosphere and tone that lets men know they are welcome, that they are central to the program.

If men come to the clinic and see male staff, if there are pictures of men with their children on the wall, if they are warmly greeted when they come to their first appointment — these make a difference. Men need messages of encouragement. They need to know that they are part of the structure. The men need to know they are valuable to their families and to their children. The more such messages are displayed in clinic settings, the more a lot of dark doors that have been closed will be open.

❑ Make it easy for men to get involved.

Unfortunately, for many fathers of color, there has been a long history of bad blood. In order to make changes happen, people must learn to trust the system again. Men are very sensitive to how they're perceived. Even though many men set a tone that they are really tough or macho, there is a side of them that wants to be cared for and nurtured. They want someone to initiate their involvement without their having to ask for it or doing a song and a dance to make it happen.

❑ Develop creative, innovative ways to reach men caring for children with HIV.

Caring for a child with serious health concerns takes all members of the family mobilized at the highest level. We have to get past the cultural barriers life has taught us and look at how we can support everyone. Many Hispanic men have been taught that they are to be the "strong" members of the family, that men and women have certain roles that must not be compromised. A lot of African-American men in Men on Board are just looking for respect, a place to stand and be valued. All of us must give up some ground so that we can create a better atmosphere for families.

❑ Demonstrate commitment to the men.

Programs must have substance, something with which men can identify. Give male caretakers something tangible, something they can reach, some goals that aren't impossible to attain. Support them in reaching these goals, so they in turn can support someone else. Men need safe havens, places where they can learn without feeling alienated. The Men on Board program at the University of Miami has connected with a lot of these men. They have embraced learning about medical care for their children and about positive parenting. They have learned that they are great assets to the children they are entrusted to care for.

❑ Encourage ownership.

Providers must look at the infrastructure of their programs and assess their history of involvement or lack of involvement with men. Only then can they establish a new history and add components of support that will help men feel better about their parental responsibilities. The men must believe that this is their program, that they have ownership for the outcomes, "This is ours. We are creating this for ourselves and our children." With this ownership in place, there is no turning back. This is a win-win situation for all of us.

Source: Ronnie Nanton, Men on Board

Project Brotherhood

Project Brotherhood, a program of Woodlawn Health Center in Chicago, focuses on special health issues facing black men. The project is one of 30 programs within the Ambulatory and Community Health Network of the Cook County Bureau of Health Services. Project Brotherhood was formed by Woodlawn staff who decided to be proactive about black men's health, with the goal of raising health awareness among black men and supporting their efforts towards improved health behaviors. Programs and services were determined based in part on the results of a series of focus groups, and two African-American social workers were hired part-time to staff the project.

Project Brotherhood serves a broad and diverse constituency, including trauma victims, men who have been incarcerated, gay men, and both single and married fathers. Project Brotherhood offers men an array of services, and they don't need to come for medical reasons. Health care services include physical exams, drug testing, and health seminars on topics like HIV, prostate cancer, and nutrition. Project Brotherhood also offers job skills development — including help with resume writing and Internet job searches — and referrals for legal counseling, victim assistance, and GED preparation. Project Brotherhood holds three-hour meetings every Thursday afternoon. On average, 50 men attend each week, participating in an agenda that encompasses topical discussions, a parenting class — most of the men are non-custodial parents — and life skill development and community service. There is also ongoing discussion of sexually transmitted diseases, including HIV.

Now three years old and experiencing rapid growth, Project Brotherhood is working on developing increased male leadership and hoping to add a youth-specific component, as well as a training module for graduate students and health care providers. Current trainings are completed in collaboration with the CARE Act's AIDS Education and Training Program, and the project also works with the local Red Cross.

Men's Educational Needs and Services

> We must be partners in this work. We leave the personalities and the politics at the door; AIDS is bigger than any one of us.
>
> — Lenny Rabb

Male caregivers and professionals working together comprise a new program in greater New York, Men's Educational Needs and Services (MENS). MENS, which is in its early stages of development, is dedicated to enhancing male involvement in health care settings.

MENS is open to all men and is reaching a diverse population that encompasses biological fathers, uncles, grandfathers, and other extended family members; foster and adoptive parents caring for children with HIV, including gay men; and stepfathers and men with a variety of other caretaking relationships, such as mothers' boyfriends or significant others.

Knowing that there is more power in numbers than in a lone voice, MENS is working slowly and carefully to build and sustain an organization. MENS is supported by an advisory board that consists of seven male caregivers, two CARE Act Title IV providers, and a researcher/practitioner from a local university. MENS has developed criteria for membership on this board, with the roles and responsibilities of membership carefully defined. The program hopes to add new members to the board, including a physician, a fundraiser, an advocate, and a lawyer or person knowledgeable about legal issues. MENS also plans to apply for nonprofit status to diversify their fundraising options.

In order to expand support for males caring for children living with HIV, MENS hopes to develop a curriculum that captures what they are learning to help health care providers develop father-friendly services in hospitals, clinics, and other health care settings.

Chapter Eight | Final Thoughts — Transformation and New Understanding

Raising a child with HIV is stressful and often overwhelming. Yet, out of the many obstacles comes an understanding about the value a man has in a child's life. Men talk about being changed for the better — transformed — and learning powerful lessons about the importance of fatherhood.

> I'm a good father. Most of the men I know are. I'm a recovering addict, a man who's living with AIDS, and I'm trying to do the best that I can in raising my children and my son who is positive. I want to see change for men while I'm living, not when I'm gone. I want it now.

> I feel proud of my daughter and proud of myself — that I'm a damn good father.

Valuing Fathers as Essential to Family-Centered Care

> The new attention devoted to fathers is not intended to lessen the focus on the important role that mothers play in their children's lives, but rather to highlight the fact that fathers are important, too. (NCES, 1998a)

Whether developing policy, programs, or curricula, start from a willingness to involve men, even when it appears they are not interested. The man who gets involved may not be the child's biological father; any man who emotionally touches a child's life can be a superb support. This includes grandfathers, stepfathers, extended family members, neighbors, and mothers' boyfriends and significant others. Allowing men to settle into the old, comfortable roles and routines they know best is a loss for the entire family. Encourage and expect the involvement of all family members, men included.

Value a father's offerings as different from a mother's. Many men want to use their problem-solving skills to help their children, and they often enjoy being physical and playful with them. Promoting and accepting such differences helps keep lines of communication open between male caregivers and health care providers. Men will make mistakes. Help them learn from them rather than feel embarrassed or humiliated. Many men do not have models of parenting that are highly nurturing, caretaking, or self-disclosing, but they can learn — and they want to learn. As one father says:

> My son has taken me to a new level of understanding about what counts in life. I really didn't have a sense of what being a parent was all about and what caring for a child was like until I became his primary supporter. I know my son will fight for what he wants, and this gives me encouragement that I can go through it also. It's a really overwhelming lesson that gives real joy to my life. Without him, I think I'd still be at ground zero.

Although writing about mothers, Weingarten (1994) recognizes the vital importance of fathers as well: "We desperately need to make the case for creating conditions that allow fathers to be as competent as mothers. It is adequacy, not just absence, we desperately need to address" (p.140).

Health care providers have a chance to create partnerships that bring lasting change and powerful systems of support for fathers and their families. Through these partnerships, men will gain new understanding about the worth they bring to the lives of their children.

> Fathers…
> You have rich milk
> For your children's souls.
> Feed them that the
> Earth might become a
> More compassionate place
> For all of us.
> (Anonymous, 1996)

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Appendix A | Men on Board: Building a Male Caregivers Program

The Miami Family Care Program, a CARE Act Title IV program at the University of Miami School of Medicine, provides health care and psychosocial services to families living with HIV disease. A multidisciplinary team of professional and consumer staff works through the Departments of Obstetrics and Gynecology and Pediatrics to offer care and support to women, children, youth, and families living with and affected by HIV and AIDS.

Need and Program History

During a routine review of the Miami Family Care Program, staff realized that the number of male caregivers had increased dramatically over the years. Among the clients in the program, social work staff identified over 75 male caregivers. These men were fathers, guardians, stepfathers, grandfathers, uncles, and other extended family members, as well as mothers' partners and significant others, all of whom were playing meaningful roles in the lives of women and children living with HIV/AIDS. Twenty-six of the men were single parents.

Traditionally in the Miami Family Care Program, women had been the sole caregivers for themselves and their children. Men rarely participated in clinic visits or in health care decision making for the children. Once the Miami Family Care Program staff identified men as an underserved population, however, it was clear that a service component should be developed to address the needs of these caregiving men.

The first step was hiring a male clinical social worker to offer the men psychosocial support and case management services and to facilitate a variety of support groups aimed at males in the program. Consumer participation in the support process was an invaluable asset from the start. The father of a child in the Family Care Program grew into a consumer advocate role for other men in the program; his life experiences as a single father of an HIV-infected child and as a consumer of clinic services himself made him ideally suited to this role. Eventually, he was hired as a peer educator, and in that position, he met all the men who came to the clinic with their children, established a relationship with them and oriented them to the program, and offered a support group as an opportunity to meet other men sharing similar experiences.

Offering male-specific support groups was key, because men rarely use the traditional support systems developed for and used by women. Acknowledging the need to develop a venue for male caregivers to meet and share their stories, the Miami Family Care Program established Men on Board (MOB). Men on Board was created as a forum for men to share feelings and concerns, as well as to pose questions and get answers about their children's illness, treatments, and other issues of concern to them. Among these concerns are parenting, discipline, permanency planning, Medicaid and other benefits, HIV counseling and testing, referrals, substance abuse, and personal relationship building.

Men on Board Today

Men on Board is staffed by a team consisting of a social worker and a peer educator. The roles and responsibilities of the social worker and the peer educator are interwoven, each supporting the other. The social worker initially meets a male caregiver at intake, where he has an opportunity to conduct a psychosocial assessment. The social worker then introduces the client to the peer educator. The peer educator also may meet the client on his own, while the client is in the clinic waiting room with his child. In the event that the client is experiencing a crisis, the social worker intervenes and assesses the need for clinical counseling and support services.

The social worker's intervention is clinical in nature, while the peer educator's role is non-clinical — support, information, and guidance, rather than therapy or other clinical services. The peer educator may share that he also cares for a child living with HIV/AIDS, but he does not go into detail. The focus of this connection between a peer educator and a male caregiver is to create the time and

opportunity for the client to share his own story — something many have never done before. It is only after the client has finished talking that available services, including a men's support group, are introduced.

After this initial meeting, the peer educator generally contacts each client by phone within a week to determine his interest taking part in Men on Board. The Men on Board support group meets every Monday evening, so that men can attend after work. Men who choose to participate are contacted each week and reminded about the upcoming meeting. Once a month an outside speaker is invited to join the group, and group members select the topics, which are okayed by the group facilitators. Child care is available.

Group support is not for everyone. Some men choose to talk to the peer educator one-on-one, and Men on Board provides this individual support, as well as the weekly group sessions. The MOB social worker/peer educator team may interact with male clients in a variety of settings, such as the inpatient unit, the outpatient clinic, or the client's home.

Every three months, Men on Board offers another supportive intervention for men and their families — a family picnic. These outings are held on Saturdays, and games and food in a relaxed outdoor location allow families the opportunity to connect with one another outside the medical environment.

Evaluation

While no formal outcome studies have been conducted to date, all of the Men on Board participants report they are benefitting from the group. They relate feeling less alone, more able to express their feelings, and better able to address difficult issues such as death and dying or drug use. They also report being more knowledgeable about the importance of administering and adhering to HIV medications. The men believe the program is an emotionally safe environment, and it is clear that Men on Board is a positive and valued addition to the Miami Family Care Program.

In the coming months, Men on Board will be carefully evaluated for effectiveness and client satisfaction, with the expectation that an expanded and more comprehensive program will be developed.

Advice from Men on Board

Strategic planning is key. Develop program goals and objectives for the program's first year. Such goals may include:

- maintaining a current and accurate client database that reflects the membership within family groups;
- conducting a needs assessment with male clients, including distributing a client satisfaction questionnaire to evaluate if existing services are meeting the needs of men;
- evaluating staff development needs with respect to serving men;
- identifying internal and external resources to support the program's activities for men; and
- finding and pursuing funding opportunities for program development or expansion.

Hiring the right staff is essential. Peer educator positions should be filled by men who have experience caring for a child or family member with HIV, such as a wife or partner. They should be comfortable sharing their life stories and being strong advocates for other men and their families.

Remember that a support group may not interest all male caregivers, especially at first. Relationship building is key; a man may need mentoring first. This can be established by offering support by phone or before or after clinic visits. Some men may never choose group support, so other forms of support should be available.

Appendix B | For More Information

Books on Fathers

Changing Roles and Personal Support

Ekulona, A. (1996). *The Healthy Start father's journal*. Baltimore: U.S. Dept. of Health & Human Services.

A thoughtful, well developed curriculum to help fathers be nurturing and knowledgeable in their parenting.

Family Resource Coalition. (1996). *Fatherhood and family support*. Chicago: Author.

An excellent series of essays to help both practitioners and family members break through stereotypes and discover new options for father involvement.

Gates, H.L. (1997). *Thirteen ways of looking at a black man*. New York: Random House.

Powerful observations and historical overview about the roles African-American men play in society and at home.

Harris, K.E. (2000, Winter). A father's guide to parenting: Building a program of education and support for fathers. *America's Family Support Magazine*, *18*(4).

Concrete suggestions to heighten male involvement and empower men. Available online at: www.frca.org/content/pub_proddef.htm.

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An outstanding survey of fatherhood from a cultural and anthropological viewpoint.

Lamb, M. (1996). *The role of the father in child development*, New York: Wiley & Sons.

A landmark book focused on research and theory regarding the importance of men in the lives of children.

Levang, E. (1998). *When men grieve: Why men grieve differently and how you can help*. Minneapolis: Fairview Press.

Poignant stories that radiate light and understanding on the differences and similarities in how men and women grieve.

Levine, J., Murphy, D., & Wilson, S. (1993). *Getting men involved: Strategies for early childhood programs*. New York: Scholastic, Inc.

Concrete suggestions for increased male involvement, including a discussion of programs that are making a difference in the lives of men and their families.

Levine, J., & Pitt. E. (1995). *New expectations: Community strategies for responsible fatherhood*. New York: Families and Work Institute.

A systems approach to involving fathers; a look at the obstacles to male involvement and how they can be overcome.

Mincy, R.B. (1994). *Nurturing young black males: Challenges to agencies, programs, and social policy*. Washington, DC: Urban Institute Press.

A review of the educational, employment, and economic factors that influence and limit adolescent black males.

Ooms, T., Cohen, E., & Hutchins, J. (1995). *Disconnected dads: Strategies for promoting responsible fatherhood*. Washington, DC: The Family Impact Seminar.

An in-depth look at the American family and how men can learn essential skills and values for responsible parenthood.

Osherson, S. (1995). *The passions of fatherhood*. New York: Fawcett Columbine.

An exploration, using personal experiences as a basis for discussion and learning, of crucial issues men face, such as marriage, raising children, and balancing work and family.

Parke, R.D., & Brott, A.A. (1999). *Throwaway dads*. Boston: Houghton Mifflin.

An examination of the barriers and myths that restrict men's involvement with their children and their families.

Pruett, K. (2000). *Fatherneed: Why father care is as essential as mother care for your child*. New York: The Free Press.

An extraordinary book about the need for fathers to be fully involved in the lives of their children — practical, concrete suggestions about how men can fully realize their parenting skills without competing with mothers in the process.

Raising a Child with Special Needs

Berube, M. (1996). *Life as we know it: A father, a family, & an exceptional child*. New York: Pantheon Books.

A deeply personal and philosophical look at the many issues fathers face raising a child with special needs.

May, J. (1997). *Fathers of children with special needs: New horizons*. Bethesda, MD: Association for the Care of Children's Health (ACCH).

An analysis and discussion of fathers' roles within the health care system and concrete strategies for increasing and supporting their involvement. Available from: Fathers Network, 16120 NE Eighth Street, Bellevue, WA 98008.

Meyer, D.J. (Ed.) (1995). *Uncommon fathers: Reflections on raising a child with a disability*. Bethesda, MD: Woodbine House.

A series of powerful, poignant essays about fathers and how the experience of being a dad to children with special needs has changed their lives; insights for both family members and providers.

Naseef, R. (2001). *Ordinary parents, exceptional children*. Baltimore: Paul H. Brookes.

An honest, searching book about one man's journey to come to terms with having an autistic son. The author, a psychologist, shares his thoughts about grief, male-female differences, siblings, and letting go of expectations.

Other Media on Fathers

Videotapes

(1999). *ABC Primetime Special: The story of fathers and sons*. Available by calling: (866) 892-2222.

Association for the Care of Children's Health. (1994). *Pediatric AIDS: A time of crisis.*

Fatherhood USA (1998). *Dedicated, not deadbeat*. Available by calling: (800) 743-2828.

Fatherhood USA (1998). *Juggling family and work*. Available by calling: (800) 743-2828.

Kauffmann, S. (Producer). (1994). *Show your love*. Boston: College of Communications, Boston University. Available by calling: (617) 353-3483.

National Fathers Network. (1996). *Equal partners: African-American fathers and systems of health care*. Bellevue, WA: Author. Available from: Fathers Network, 16120 NE Eighth Street, Bellevue, WA 98008, (425) 747-4004, ex. 218.

National Fathers Network (1989). *Special kids, special dads: Fathers of children with disabilities*. Bellevue, WA: Author. Available from: Fathers Network, 16120 NE Eighth Street, Bellevue, WA 98008, (425) 747-4004, ex. 218.

Organizations Serving Fathers and Families

Center on Fathers, Families, and Public Policy, c/o Family Support America, 20 North Wacker Drive, Suite 1100, Chicago, IL 60606, (312) 338-0900, www.frca.org/content/home. htm

> Examines the legal and social service support systems available to never-married, low-skilled, and low-income fathers. Educates policy makers and the public about the need for public policies that help fathers become completely involved with their children.

Fathers Resource Center, c/o Prevention Alliance, Loring Park Office Building, 430 Oak Grove Street, Suite 105, Minneapolis, MN 55403, (612) 874-1509, www.fathering.com/frc/index.shtml.

> Offers a broad base of services and resources for fathers, including support programs, legal assistance, parenting classes, and a newsletter.

Institute for Responsible Fatherhood and Family Revitalization, 146 19th Street NW, Suite 800, Washington, DC 20036, (800) 7-FATHER, (202) 293-4420, www.responsiblefatherhood.org

> Supports the efforts of young men to become responsible, mature, resourceful fathers. The Institute is a non-traditional community-based organization that creates an environment where young fathers can make life safe for themselves, their children, and the mothers of their children. Weekly father and mother support groups are offered, as well as group counseling and family outreach. Outreach to incarcerated fathers is a special component of the Institute.

Manpower Demonstration Research Corporation, 3 Park Avenue, New York, NY 10016, (212) 532-3200

> Conducts primary research on a variety of issues related to helping families become economically independent, including teen pregnancy and fatherhood. Manpower uses this research to design and implement demonstration projects throughout the United States.

MELD for Young Dads, 123 North Third Street, Suite 507, Minneapolis, MN 55401, (612) 332-7563

> Focuses on parent education and support programs for men, 15-25. MELD provides curriculum covering child development, health and nutrition, parenting skills — including problem solving and communication — and child guidance.

National Center for Fathering, 10200 West 75th Street, Suite 267, Shawnee Mission, KS 66204, (913) 384-4661, www.fathers.com/Main.html

Develops resources to strengthen community-based efforts addressing the need for more and better fathering. The Center develops training programs for fathers from diverse cultural communities and encourages and supports special fathering groups for divorced fathers, stepfathers, military fathers, and incarcerated fathers. They offer two-day seminars to teach men to be better fathers, and publish the magazine, *Today's Father*.

National Center on Fathers and Families, Graduate School of Education, University of Pennsylvania, 3700 Walnut Street, Philadelphia, PA 19104, (215) 686-3910, www.ncoff.gse.upenn.edu

Develops and implements practice-focused, practice-driven research to expand knowledge on father involvement and families. The Center is involved in program development, policy research, engaging policy makers, and disseminating information.

National Fatherhood Initiative, 101 Lake Forest Boulevard, Suite 360, Gaithersburg, MD 20877, (301) 948-0599, www.fatherhood.org/index.html

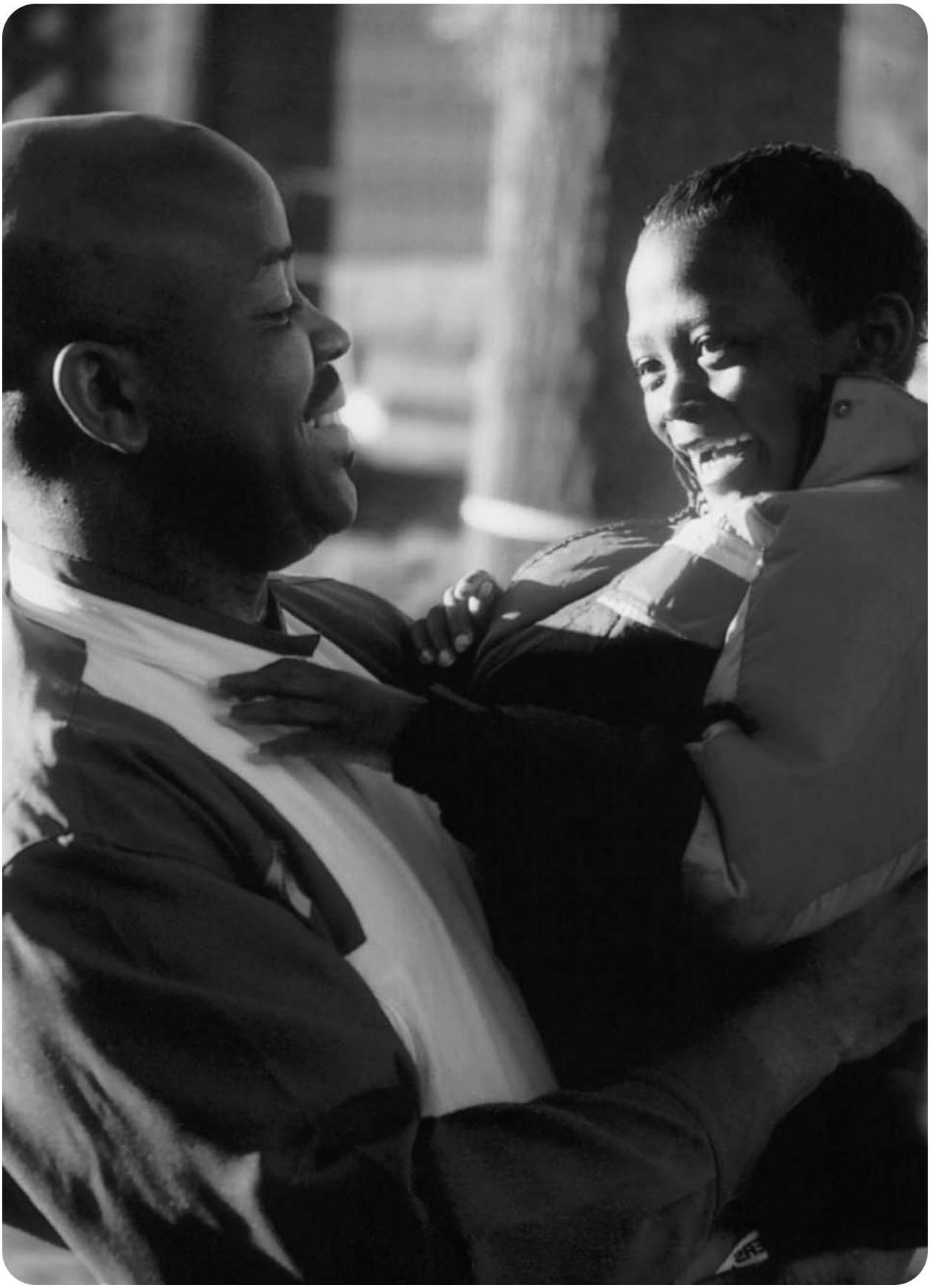
Conducts public awareness campaigns promoting responsible fatherhood, organizes conferences and fatherhood forums, provides resource materials to organizations seeking to establish support programs for fathers, publishes a quarterly newsletter, conducts research on fatherhood, works to enhance the effectiveness of public policies to encourage responsible fatherhood, and disseminates informational material to men seeking to become more effective fathers.

National Practitioners Network for Fathers and Families, 1003 K Street NW, Suite 565, Washington, DC 20001, (202) 737-6680, www.fatherhoodproject.org/npnpage.htm

Shares information on practice, policy, funding, and research to social service practitioners so they may coordinate their efforts in promoting father involvement.

Washington State Fathers Network, Kindering Center, 16120 NE Eighth Street, Bellevue, WA 98008, (425) 747-4004, ex 218, www.fathersnetwork.org

Provides support and resources to fathers and families of children with special health care needs and developmental disabilities, as well as training and technical assistance, regional conferences, and curriculum on issues relating to enhanced father involvement. The Fathers Network produces a tri-yearly newsletter and offers an extensive web page. Currently there are 15 statewide programs.



The information and insights in this monograph come in large part from the work of the National Fathers Network. For 15 years, the Fathers Network — which was funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, Department of Health and Human Services — developed supports and resources for fathers and families of children with developmental disabilities and special health care needs. For over a decade, there was a special focus on men raising children with HIV. Visit the Fathers Network web site at: www.fathersnetwork.org for more information about videos, monographs, and curriculum. Or contact the Fathers Network, 16120 NE Eighth Street, Bellevue, WA 98008-3937, (425) 747-4004, ex. 218.

Through **education, training and advocacy,** **AIDS Alliance** for Children, Youth & Families addresses the **needs** of **children, youth and families** affected by **HIV** and **AIDS.**

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