

PREVENTION WORKS!

CHILDREN LIVING IN STRESSFUL ENVIRONMENTS: A RESOURCE KIT

VI.d. Children in Families With Disabilities, HIV, or Chronic Illness

Discussion

Illness or disability in the family can have a range of effects, negative and positive, on the children. Children in families with disability, HIV, or chronic illness often have to face real-life concerns at an earlier age than most. Although they can be just as playful as their peers, these children sometimes grow up seeing life as “serious business.” Prevention professionals need to pay attention to the ways that long-term health issues can put stress on families and consequently raise the children’s risk for substance abuse problems. They also need to recognize the potential strengths of parents and families with disability or illness and how these advantages may help prevent substance abuse in the children.

When one family member’s health status is challenged or unpredictable, the whole family is affected. While all children rely on their parents to help them feel safe and secure, parents in families with health concerns may be too preoccupied and overwhelmed to provide this attention. There may be conflict within the family when coping strategies fall short. The children may even be called upon to *provide* care to an ill family member. As a result, psychological distress can easily spread throughout the family.¹

Families affected by HIV experience both the practical challenges of this unpredictable disease and the emotional challenges of witnessing the gradual decline and early death of a family member. In addition, many families affected by HIV already have a substance abuse problem that may have led to the infection to begin with. This combination of factors results in a high rate of emotional distress for children in these families.²

As we know, children of addicted parents are at the highest risk, genetically and environmentally, to develop alcohol or drug abuse problems. Substance abuse affects how the whole family functions, often creating a troubled environment that can lead to substance abuse problems in the children.³ Families struggling with illness or disability are at particular risk for

¹ Holmes, A. M., and Deb, P. (2003). The effect of chronic illness on the psychological health of family members. *Journal of Mental Health Policy and Economics*, 6(1), 13–22.

² Stone, H. Z. (May 2001). *Group work with HIV/AIDS-affected children, adolescents, and adults: A curriculum guide*. Washington, DC: Family Ties Project and Consortium for Child Welfare. Retrieved March 20, 2008, from www.familytiesproject.org/Documents/GroupCurriculum.pdf.

³ National Association for Children of Alcoholics. (n.d.). *Children of addicted parents: Important facts*. Retrieved January 6, 2008, from www.nacoa.org/pdfs/addicted.pdf.

substance abuse. Parents or other family members dealing with long-term health problems may abuse alcohol or drugs in an attempt to cope with depression, anxiety, pain, and the pressures of life with an illness or disability.⁴ Thus, it is important to include these families, especially the children, in prevention efforts.

While a disability or illness in the family has the potential to create hardships for the children, it is important to note that it can also provide opportunities for a family to bond closely and develop resilience—factors that protect against substance abuse in children.⁵ In addition, if a disability in the family provides the child with more opportunities to engage in acts of “required helpfulness,” it may help protect him or her from substance abuse—even if the family has an existing substance abuse problem.⁶

Families With Disability or Chronic Illness

Disabilities and illnesses come in many forms and so do families’ experiences with them. An unpredictable, hard-to-manage health condition can contribute to anxiety, conflict, and depression in a family, drain financial resources, and leave the children without adequate parental care. In addition, a progressive, terminal condition can bring feelings of grief, powerlessness, and loss of structure to the family environment. Other health conditions can be permanent but more stable, allowing the affected individual to maintain good health, fulfill caregiving roles, and function in daily life, with assistance if necessary.⁷

People with disabilities, including chronic illnesses, are at a heightened risk for substance abuse. They can experience risk factors such as isolation, unemployment, lack of education, abuse, physical pain, and poverty. People with disabilities often take one or several medications, and, therefore, are at greater risk for accidentally or intentionally overusing them or mixing them with alcohol or other drugs.⁸

Sometimes, family members and health care providers may be reluctant to confront a substance abuse problem because they believe that the ill or disabled individual needs it—perhaps is even *entitled* to it—as the only means to tolerate emotional and physical pain. Unfortunately, even when everyone does recognize there is a substance abuse problem, it can be difficult for a person with a disability or chronic illness to obtain accessible treatment and recovery services.⁹

⁴ U.S. Department of Health and Human Services (HHS), Office on Disability. (n.d.). *Substance abuse and disability*. Retrieved January 6, 2008, from www.hhs.gov/od/about/fact_sheets/substanceabuse.html.

⁵ American Academy of Pediatrics. (June 2007). *Parenting corner Q&A: Chronic illness*. Retrieved January 6, 2008, from www.aap.org/publiced/BK5_ChronicIllness_Siblings.htm.

⁶ National Association for Children of Alcoholics. (August 1998). *Children of alcoholics: Important facts*. Retrieved March 20, 2008, from www.nacoa.net/impfacts.htm.

⁷ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

⁸ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

⁹ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

Families With HIV

HIV creates serious mental health concerns for affected children and families, who can experience:

- **Anxiety** in response to the unpredictability of the virus, which can disrupt the structure and routines that create a sense of family security;
- **Depression** from living with a chronic terminal illness, awaiting the suffering and death of a family member, and planning for guardianship and other arrangements in anticipation of this loss. In addition, children can become emotionally numb to avoid constant grieving;
- **Stigma, secrecy, and shame** about the HIV diagnosis. Some parents do not tell their children, but are unavoidably preoccupied and overwhelmed. Other parents disclose the diagnosis to the children, but demand secrecy for fear of being stigmatized in the community and extended family. Children may feel shame, fear, and distrust as a result;
- **Family dysfunction** as parent/child and sibling relationships are disturbed by anxiety, depression, and the demands of caregiving, as well as feelings of helplessness, guilt, and anger. Existing substance abuse (a primary risk factor for American women with HIV) may already be hurting family members' ability to communicate, support each other, and develop healthy coping strategies;
- **Compromised parenting ability** when a parent is too ill or overwhelmed by caring for an ill family member; and
- Other existing **disadvantages** that disproportionately affect families living with HIV: poverty, lack of education, mental illness, substance abuse, crime, violence, abuse, and traumatic stress.^{10,11}

Many families affected by HIV already have a substance abuse problem as well. Injection drug use accounts for more than one-third (36 percent) of all AIDS cases in the United States, and fully 57 percent of all AIDS cases among women have been attributed to injection drug use or sex with partners who inject drugs. Noninjection drugs also play a role in HIV transmission when users trade sex for drugs or money or when they engage in risky sexual behaviors while under the influence.¹²

¹⁰ Stone, H. Z. (May 2001). *Group work with HIV/AIDS-affected children, adolescents, and adults: A curriculum guide*. Washington, DC: Family Ties Project and Consortium for Child Welfare. Retrieved March 20, 2008, from www.familytiesproject.org/Documents/GroupCurriculum.pdf.

¹¹ National Abandoned Infants Assistance Resource Center. (Spring 2002). Mental health challenges in HIV positive women, adolescents and children. *The Source*, 11(2), 1-4. Retrieved March 20, 2008, from http://aia.berkeley.edu/media/pdf/source_vol11_no2.pdf.

¹² Centers for Disease Control and Prevention (CDC), Divisions of HIV/AIDS Prevention. (May 2002). *Drug-associated HIV transmission continues in the United States*. Atlanta, GA: CDC. Retrieved March 20, 2008, from www.cdc.gov/hiv/resources/factsheets/PDF/idu.pdf.

Most HIV-positive women in the United States are mothers with dependent children who face considerable emotional challenges because of the mother's illness. Studies show that these children are very likely to experience a range of psychological and behavioral problems, notably separation anxiety among 8- to 10-year-olds. These problems seem to improve when the mother's physical and mental health improves, but they worsen in response to new stresses, such as the mother's hospitalization, economic problems, or social isolation. These children should be screened periodically for emotional and behavioral problems that may result from these changing circumstances.¹³

Social support, defined as "the existence or availability of people who let an individual know that they care about, value, and love them," can significantly help adolescents of parents with HIV lower their emotional distress, avoid problem behaviors, and nurture their self-esteem. These teens experience less depression and fewer conduct problems when they have more people in their lives who are supportive about the parent's illness and help out in times of trouble. However, these adolescents experience more distress and problem behaviors when their support providers engage in destructive behaviors such as substance abuse, unprotected sex, or crime.¹⁴

Parental Disability or Illness

Nationwide, nearly 9 million parents have disabilities, constituting 15 percent of all parents in the United States.¹⁵ While disability may limit some individuals' ability to parent, it greatly depends on the nature of the disability and the degree of access to assistive services, adaptive technology, and parenting education and support (which is usually more readily available to parents without disabilities). Few communities have developed systems of care for parents with disabilities and their children.¹⁶ Ultimately, however, studies of parents with various conditions have shown that "multiple, cumulative, and synergistic sources of stress" have the most significant effect on children's well-being, rather than a parent's disability per se.¹⁷

Children and other family members can experience such myriad stresses when a parent's health status is dramatically compromised by a progressive disability or illness. Parental school involvement, child monitoring, and positive family activities and routines can suffer or completely go by the wayside when a parent or other family member's illness takes center stage.¹⁸

If a parent experiences debilitating fatigue caused by a health condition, he or she may be unable to attend to the children. If a parent is struggling with a mental illness and its behavioral effects,

¹³ Bauman, L. J., Silver, E. J., Draimin, B. H., and Hudis, J. (2007). Children of mothers with HIV/AIDS: Unmet needs for mental health services. *Pediatrics*, 120(5), e1141–e1147.

¹⁴ Lee, S. J., Detels, R., Rotheram-Borus, M. J., and Duan, N. (2007). The effect of social support on mental and behavioral outcomes among adolescents with parents with HIV/AIDS. *American Journal of Public Health*, 97(10), 1820–1826.

¹⁵ Through the Looking Glass. (March 8, 2007). *Parents with disabilities*. Retrieved March 20, 2008, from <http://lookingglass.org/parents/>.

¹⁶ Through the Looking Glass. (December 13, 2005). *Frequently asked questions (FAQ)*. Retrieved March 20, 2008, from <http://lookingglass.org/about/faqdetails.php#TLGPI>.

¹⁷ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

¹⁸ Hogan, D. P., Shandra, C. L., and Msall, M. E. (2007). Family developmental risk factors among adolescents with disabilities and children of parents with disabilities. *Journal of Adolescence*, 30(6), 1001–1019.

it may contribute to a stressful family environment, and the children may have a higher risk, genetically and environmentally, for developing mental illness as well.¹⁹ HIV or other chronic terminal illnesses can introduce an atmosphere of death and grief to the home. The disintegration of routine and neglect of basic needs can lead to conflict and a breakdown of family ties. Psychological distress can become contagious throughout the family.²⁰

Parental disability can raise unique issues and challenges, even when the parent's health status is stable and the children are well cared for. Physical and attitudinal barriers affect not only the individual with a disability, but the whole family. When parents with disabilities experience stigma, isolation, economic disadvantages, transportation issues, and other disparities, their children suffer also. Although parents with disabilities are frequently assumed to disproportionately and inappropriately rely on their children for assistance, some studies show that they take great pains not to overburden their children. Nevertheless, when personal assistance services are unobtainable or unaffordable, children may wind up performing substantial and stress-inducing caregiving tasks.²¹

Child Disability or Illness

When one child has a disability or chronic illness, it affects the whole family, including siblings.²² Children can experience many challenging emotions when a brother or sister has a long-term health issue. On the other hand, a child's disability can strengthen family bonding, increase empathy and tolerance for differences, and provide ample opportunities for siblings to participate in family life and help someone they care about— environmental factors that protect against substance abuse.²³ It is especially important to note this potential for positive outcomes in light of clinical literature's strong emphasis on the burdens posed to families, siblings, and society by children with disabilities.²⁴

Children's responses to sibling disability vary greatly, partly because different conditions impact families in different ways.²⁵ It can be frightening to watch a sibling struggle with a chronic or life-threatening condition. Brothers and sisters can feel guilty that they are not sick as well. Young children may worry that their jealous or mean thoughts actually caused the sibling's health problem. Children may feel neglected when parents have to give extra time and attention to an ill or disabled sibling. They may feel uncomfortable if strangers stare or make unkind comments about their sibling. They may resent having to do more chores than their sibling, then

¹⁹ American Academy of Child and Adolescent Psychiatry. (July 2004). *Children of parents with mental illness*. No. 39. Retrieved March 20, 2008, from www.aacap.org/cs/root/facts_for_families/children_of_parents_with_mental_illness.

²⁰ Holmes, A. M., and Deb, P. (2003). The effect of chronic illness on the psychological health of family members. *Journal of Mental Health Policy and Economics*, 6(1), 13–22.

²¹ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

²² Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

²³ National Association for Children of Alcoholics. (August 1998). *Children of alcoholics: Important facts*. Retrieved March 20, 2008, by www.nacoa.net/impfacts.htm.

²⁴ Olkin, R. 1999. *What psychotherapists should know about disability*. New York: Guilford Press.

²⁵ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

feel guilty for feeling resentful. Similarly, they may feel guilty about normal feelings of sibling rivalry and jealousy.²⁶

Several approaches can help children cope with the stressful aspects of their sibling's disability or illness and develop resilience. Parents and other caring adults can strengthen and reaffirm their individual relationships with the children by spending one-on-one time with each of them. Giving children age-appropriate information about the ill or disabled child's health situation helps maintain communication and reduce fear. Family meetings can also give everyone—adults and children—a forum to constructively voice feelings, share information, and make decisions together.²⁷

Child Caregivers

Research has only begun to show that children often play an important role in providing care when there is illness or disability in the family. About 1.4 million children between the ages of 8 and 18 in about 906,000 households nationwide assist a disabled or ill family member, usually (but not always) in cooperation with another family caregiver. Of these children, 38 percent provide care for a grandparent and 34 percent provide care for a parent.²⁸ Caregiving tasks include household chores, meal preparation, shopping, dressing, feeding, bathing, bathroom assistance, administering medicine, helping the care receiver move around the house or community, keeping him/her company, providing emotional support, managing paperwork, paying bills, talking to health care providers, and arranging outside services.²⁹

Children experience both benefits and disadvantages from playing a caregiving role. Child caregivers feel especially appreciated for help they give, compared to noncaregivers. Child caregivers are also less likely to feel too much is expected from them or to feel angry about their obligations.³⁰ On the other hand, although child caregivers participate in the same educational and social activities as their peers, some may feel distress, isolation, and sadness and develop behavioral or school problems—particularly boys. Compared to boys who are not caregivers, caregiving boys are more likely to feel sad and twice as likely to feel that it is useless to show their feelings.

In general, child caregivers are more likely to show anxious or depressed behavior and sometimes feel that no one loves them and that they are worthless or inferior. Older caregivers (12 to 18 years old) are also more likely than noncaregivers to exhibit antisocial behavior such as cheating, lying, lacking remorse for misbehavior, meanness, disobedience, destructiveness, and

²⁶ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

²⁷ Phillips, R. H. (Fall 2003). Meeting of the minds: Family meetings can help everyone cope better with lupus. *Lupus Now*, 1(1), 8–9.

²⁸ American Association of Caregiving Youth. (August 3, 2007). *U.S. and international caregiving facts*. Boca Raton, FL: American Association of Caregiving Youth. Retrieved March 20, 2008, from www.aacy.org/caregivingfacts.htm.

²⁹ National Alliance for Caregiving. (September 2005). *Young caregivers in the U.S.: Findings from a national survey*. Bethesda, MD: National Alliance for Caregiving. Retrieved March 20, 2008, from <http://caregiving.org/data/youngcaregivers.pdf>.

³⁰ National Alliance for Caregiving. (September 2005). *Young caregivers in the U.S.: Findings from a national survey*. Bethesda, MD: National Alliance for Caregiving. Retrieved March 20, 2008, from <http://caregiving.org/data/youngcaregivers.pdf>.

difficulty getting along with teachers. Caregiving children of both genders in low-income minority households experience more stress and report less help in carrying out their caregiving tasks. In addition, one in five caregivers say their caregiving responsibilities have made them miss a school activity or an after-school activity, 15 percent say caregiving has kept them from doing schoolwork, and 8 percent say it has made them miss homework. In a recent study, 22 percent of high school dropouts said they left school to care for a family member.³¹

When a family can't obtain appropriate adult assistance, children may wind up performing caregiving tasks that are inappropriate to their age, gender, or emotional development.³² When children assume adult roles or parental responsibilities before they are emotionally or developmentally ready, they can experience emotional distress and problem behaviors such as substance abuse, sexual activity, and conduct problems.³³

Facts

- At least 8 million, or 11 percent, of families in the United States with children under age 18 have one or more parents with a disability.³⁴
- Eighteen percent of African-American families and more than 16 percent of Hispanic families have a parent with a disability.³⁵
- Thirteen percent of children without disabilities and one-third of children with disabilities grow up in families in which at least one parent has a disability.³⁶
- After living with an ill parent, about 80,000 children in the United States have been orphaned by AIDS.³⁷

³¹ Bridgeland, J. M., DiIulio, J. J., and Morison, K. B. (March 2006). *The silent epidemic: Perspectives of high school dropouts*. Washington, DC: Civic Enterprises, LLC. Retrieved March 20, 2008, from www.civicerprises.net/pdfs/thesilentepidemic3-06.pdf.

³² Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

³³ Stein, J. A., Riedel, M., and Rotheram-Borus, M. J. (1999). Parentification and its impact on adolescent children of parents with AIDS. *Family Process*, 38(2), 193–208.

³⁴ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

³⁵ Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

³⁶ Hogan, D. P., Shandra, C. L., and Msall, M. E. (2007). Family developmental risk factors among adolescents with disabilities and children of parents with disabilities. *Journal of Adolescence*, 30(6), 1001–1019.

³⁷ Rotheram-Borus, M. J., Lee, M. B., Gwadz, M., and Draimin, B. (2001). An intervention for parents with AIDS and their adolescent children. *American Journal of Public Health*, 91(8), 1294–1302.

- About 1.4 million children between the ages of 8 and 18 in about 906,000 households nationwide assist a disabled or ill family member.³⁸
- Although far more adult females than adult males are caregivers, the child caregiver population is evenly divided between girls and boys.³⁹

Federal Resources

National Dissemination Center for Children with Disabilities

www.nichcy.org/

Funded by the Office of Special Education Programs (OSEP) of the U.S. Department of Education, this Center provides information on disabilities in children and youth; programs and services for infants, children, and youth with disabilities; IDEA, the Nation's special education law; No Child Left Behind, the Nation's general education law; and research-based information on effective practices for children with disabilities.

National Rehabilitation Information Center (NARIC)

www.naric.com/

NARIC collects and disseminates the results of research funded by the National Institute on Disability and Rehabilitation Research (NIDRR) and other Federal entities to serve anyone, professional or lay person, who is interested in disability and rehabilitation. NIDRR operates in concert with the Rehabilitation Services Administration (RSA) and OSEP within the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education.

Substance Abuse Resources and Disability Issues (SARDI)

www.med.wright.edu/citar/sardi/index.html

The SARDI Program at Wright State University's Boonshoft School of Medicine in Dayton, OH, seeks to improve the quality of life for persons with disabilities, including those who are concurrently affected by behavioral health issues, by conducting collaborative and participatory research, developing intervention approaches and training, and disseminating related information. In 2004, NIDRR funded the Rehabilitation Research and Training Center (RRTC) on Substance Abuse, Disability, and Employment at SARDI.

U.S. Department of Health and Human Services (HHS) Office on Disability

www.hhs.gov/od/index.html

The Office on Disability was created in October 2002 to oversee the implementation and coordination of HHS programs, policies, and special initiatives addressing seven distinct

³⁸ National Alliance for Caregiving. (September 2005). *Young caregivers in the U.S.: Findings from a national survey*. Bethesda, MD: National Alliance for Caregiving. Retrieved March 20, 2008, from <http://caregiving.org/data/youngcaregivers.pdf>.

³⁹ National Alliance for Caregiving. (September 2005). *Young caregivers in the U.S.: Findings from a national survey*. Bethesda, MD: National Alliance for Caregiving. Retrieved March 20, 2008, from <http://caregiving.org/data/youngcaregivers.pdf>.

domains in the area of disability: community integration, education, employment, health, housing, technology, and transportation.

Private Organizations

Beach Center on Disability

www.beachcenter.org/

A permanent unit of the University of Kansas, the Beach Center conducts research; prepares graduate students; and provides technical assistance, information, and referral services to families and individuals with disabilities throughout Kansas and the world. This work helps to enhance the quality of life of families and individuals with disabilities as they progress through early diagnosis and intervention, inclusion in school, and transition to adulthood.

Family Ties Project

www.familytiesproject.org/

The mission of the Family Ties Project is to promote and preserve the well-being of children, youths, and families affected by HIV/AIDS by working with parents and caregivers to plan for the future care of their children. The Family Ties Project is funded by HHS' Abandoned Infants Assistance Program.

Through the Looking Glass (TLG)

<http://lookingglass.org/index.php>

TLG's mission is to empower parents and people with disabilities who may become parents by disseminating disability-appropriate information about parenting to parents; disability advocates; and legal, medical, intervention, and social services providers. TLG has conducted numerous research projects of national significance concerning families with disabilities since 1982. In 1998, TLG became the first National Center on Parents with Disabilities, funded by NIDRR, U.S. Department of Education.

Strategies/Programs

An Intervention for Parents With AIDS and Their Adolescent Children

www.ajph.org/cgi/reprint/91/8/1294

This study evaluated an intervention designed to improve behavioral and mental health outcomes among adolescents and their parents with AIDS. Adolescents in the intensive intervention group reported significantly lower levels of emotional distress, multiple problem behaviors, conduct problems, and family-related stressors and higher levels of self-esteem than adolescents in the standard care group. Parents with AIDS in the intervention group also reported significantly lower levels of emotional distress and multiple problem behaviors. This demonstrates that interventions can reduce the long-term impact of parents' HIV status on themselves and their children.

Clinician-Based Cognitive Psychoeducational Intervention for Families

http://nrepp.samhsa.gov/programfulldetails.asp?PROGRAM_ID=88

This approach, included in the Substance Abuse and Mental Health Services Administration's National Registry of Evidence-based Programs and Practices (NREPP), is intended for families with parents who have significant mood disorders. Based on public health models, the intervention is designed to provide information about mood disorders to parents, equip parents with the skills they need to communicate this information to their children, and open dialog in families about the effects of parental depression.

Designing Mental Health Services for Families Affected by Life-Threatening Illness

http://aia.berkeley.edu/media/pdf/source_vol11_no2.pdf, (pp. 12–15)

The Family Center (TFC) was created to address the increasing number of New York City children orphaned as a result of parental AIDS and other illnesses. TFC focuses on serving the entire family and provides fully integrated in-home legal and social services to help parents cope with serious illness and make plans for the future care of their children. Abandoned Infants Assistance grants—from the Administration on Children, Youth and Families' Children's Bureau—support several of TFC's programs. TFC has achieved success by providing clients with mental health services that emphasize recreation and fun activities and using program titles that do not mention mental health or counseling.