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The mental health needs of adolescents in families with AIDS

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THE MENTAL HEALTH NEEDS OF ADOLESCENTS IN FAMILIES WITH AIDS

by

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Abstract

THE MENTAL HEALTH NEEDS OF
ADOLESCENTS IN FAMILIES WITH AIDS

by

Barbara H. Draimin

Advisor: Dr. Irwin Epstein

This dissertation is an exploratory study of the perspectives of parents and adolescents on the mental health needs of well adolescents in families with AIDS. The methods used for this study were participant observation and focused interviews with guardians and adolescents whose families have been directly affected by AIDS. Forty families were interviewed. The data for this study were collected in 1991 while the investigator was the Director of Planning for AIDS Services within a large city government. Since the department provided comprehensive social services for people with AIDS, the affiliation provided excellent access and support for the purposes of the study. The study was partially funded by the National Institute of Mental Health through Contract # 279492.

The purpose of the study was to assess the mental health needs of adolescents in families in which at least one adult family member has AIDS. To gain information about clients, a questionnaire was used to interview both the adolescent and his/her guardian or parent.

Two groups were studied. Twenty adolescents were interviewed who had a parent living with AIDS. An additional twenty were interviewed six months after the parent with AIDS had died.

AIDS poses special and unique problems for adolescents dealing with the death of a parent. For example, all respondents were concerned about the stigma of HIV disclosure to other people both inside and outside the family. All families had difficulty knowing whom to tell about the illness.

The exploratory nature of this study, as well as the limited sample, make these findings the base work for another study. The qualitative nature of this study helped to identify the factors on which to focus in follow-up research. As a result of this exploratory study, a subsequent longitudinal study evaluating the effectiveness of two proposed intervention strategies for enhancing the mental health, behavioral and social adjustment of adolescents who have a parent living with AIDS has been designed and submitted for federal funding.

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To Dorothy and Peter Draimin
who raised this adolescent
by showing her that
a woman could be strong
and learning could be fun.

The design and execution of this study was a team effort and I was honored to be the captain. Funding the team were the National Institute of Mental Health and the Health Resources and Services Administration. Hosting the study was the New York City Human Resources Administration Division of AIDS Services and its leaders, Commissioner Barbara Sabol and Assistant Deputy Commissioner Stephen Fisher, who provided total support and encouragement. The two star players were Jan Hudis and José Segura. Other team members included Elise Ingram, Dan Sendzik, Amy Shire, Pablo Colon, Jim Duffield, Ivy Gamble, Ellen Cohen, and Anita Baskind.

The umpire who monitored every word with consistency and compassion was Irwin Epstein. The officials--Dean Bogart Leashore, Pam Reid and Gary Anderson--made astute suggestions and provided enthusiastic encouragement.

Harriet Goodman was the experienced professional whose do's and don'ts I followed religiously. Without her, I might still be searching for a topic.

My life partner, Isabell Mackie, was always cheering. She forfeited three years of recreation without a single complaint. When I became lazy, she gave me a nudge. When I overworked, she was ready with a picnic basket.

Finally, the forty families who contributed their time, thoughts and feelings gave me the perspective to live so fully this thing called life. This is their story and the most important task of this work for me was to tell it with accuracy, sensitivity, compassion and love so that others might appreciate their struggles and strengths.

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CHAPTER ONE

INTRODUCTION AND REVIEW OF THE LITERATURE ADOLESCENTS DEALING WITH DEATH

Introduction

As this review of the literature will demonstrate, the specific needs of well adolescents in families with AIDS have yet to be described. However, information from related research can be culled to examine relevant aspects of the phenomenon.

These include:

An Epidemic Update

AIDS and Adolescents

AIDS and Ethnicity

Coping With Serious Life Events

Children and Grief Reactions

An Epidemic Update

A significant and increasing number of adolescents will be impacted by living with a PWA in their families and the death of the PWA. In many cases the PWA will be the adolescent's parent, usually his/her mother.

It is projected that between 52,272 and 72,000 children in the United States will be left orphaned by AIDS deaths

(Norwood, 1989); nearly half will be between the ages of 11 and 17 (Drucker et. al. 1988).

In December, 1991, 1516 families were receiving services from the New York City Human Resource Administration's Division of AIDS services (DAS). 568 of these families had at least one adolescent aged 12-18. This number is expected to rise by 33% over the next year.

The likely death of the person with AIDS in these families is a significant stressor which will compound the already existing struggles of living with poverty, substance abuse, unstable housing and weak support systems (Wiener & Septimus, 1991). For a large percentage of these PWAs who became infected due to IV drug use, it may be common for more than one family member (often a young child) to also carry the diagnosis (Wiener & Septimus, 1991).

Drug users are often inaccurately assumed to be separated from family life. For this reason, the impact of AIDS on family functioning and mental health has not been given adequate attention. (Levine, 1990). In addition, over 90% of the families with AIDS are on public assistance and it has been difficult to study family functioning within the context of a system that financially rewards and punishes family members by where they live.

Family members of PWAs may experience stress as high as that reported by the PWA (Lamping et.al.,1991). Adolescents in these circumstances are likely to feel the impact of the

disease even more acutely than their younger siblings. Frequently there are no other adults in the household and the adolescent must take over parenting roles themselves, often without adequately developed coping skills. The necessity of tending to the needs of ill family members may entail leaving school and isolation from social support networks. Adolescents from families with AIDS may also have to cope with ridicule from peers and increased alienation (Frierson et.al.,1987).

At the same time these youth are taking on increasing responsibility at home, they must confront their own risk of infection and cope with the impending death of a parent--a traumatic event which can seriously interfere with social and emotional functioning (Siegel, Messagno & Christ, 1990). If someone else in the household has HIV, these young people will be coping with the illness and eventual loss of another person in the family . These complex stressors compound the difficult normative demands of adolescence, making these youth particularly vulnerable to poor outcomes following the death of the parent . Few services are currently in place to address the unique needs of these adolescents (Levine, 1991).

The stresses experienced by adolescents living in families with AIDS, which can include custody battles resulting in being shuffled among family members (Drucker et al, 1988) along with decreased social support and inadequate

parental supervision and caretaking, are implicated in the development of problem behaviors (Ensminger, 1990) such as high-risk sex and drug use.

Aids and Adolescents

A report was issued in November, 1991 from the New York State AIDS Advisory Council titled "Illusions of Immortality: The Confrontation of Adolescence and AIDS." This report focuses on the threat of HIV to the lives of adolescents throughout New York State. The fear is that large numbers of teens will contract HIV before they turn twenty and may not become symptomatic for a decade or more. The report is clear and concise and lists recommendations for change. In the article "AIDS in Adolescence" by Karen Hein (1989), the differences between child, adolescent and adult AIDS are described. For example, a higher percent of teenage AIDS cases are acquired by heterosexual transmission, there are a higher percentage of black and Hispanic cases, and there are conflicting legal and ethical issues regarding the informing of parents and the confidentiality of clients.

The group not yet addressed in adolescent reports and articles are the **well** adolescents already in families with AIDS. The beginnings of AIDS literature understandably focused on those with HIV or those at greatest risk. But

ten years into the epidemic, there is a need to bring attention to the effect of AIDS on adolescents and other family members. Illness impacts on the whole family--especially a new, stigmatized and terminal illness such as AIDS. We are just now beginning to confront the realities of whole families living with and dying with AIDS. (Wiener, 1991).

As John Martin (1988) points out, there is a primary epidemic of AIDS and a secondary epidemic of AIDS-related bereavement. This latter epidemic is expanding exponentially.

Peterson (1991) writes that school social workers need to consider that children are affected when their parents are infected by HIV, and not only when they suffer directly from AIDS. Teachers and social workers have not assumed that most New York families have been affected by the epidemic. There is a collusion in the theory that only 'certain' families are affected.

Adolescents living in families with a PWA are likely to experience significant adjustment difficulties leading to multiple problem behaviors, emotional distress, and disturbed interpersonal relationships.

Adolescents living in families with AIDS experience severe environmental stress, with concomitant decreases in perceived control, social support and adequate parental supervision and caretaking. This environmental

constellation is implicated in the development of problem behaviors (Ensminger, 1990) such as high-risk sex and drug use. Distressed youth use drugs as a means of alleviating unpleasant feelings (Rotheram-Borus & Koopman, In press) and coping with frustration or anticipated failure. Problem behaviors tend to cluster; individuals exhibiting high-risk sexual and drug use behaviors are also more apt to be depressed and anxious, engage in anti-social behavior, have problems in school and with the law, and attempt suicide (Ensminger, 1987). Adolescents undergoing bereavement may be especially at risk. Since over 40% of social work programs provide no training in human sexuality and primary prevention (Diaz and Kelly, 1991), the ability to intervene with adolescents is severely compromised. Social work practitioners need to provide education to family members due to their fears of acquiring the illness and the need for prevention education. (McDonell et al., 1991).

Providers who work with disadvantaged families must be willing to leave the order and comfort of office treatment. This will mean going out to poorly lit, dangerous buildings and physically entering into the families' lives. (Halpern, 1990).

Furthermore, the stigma associated with AIDS makes it all the more difficult for adolescents and their families to make use of extended family, friends and the larger community for support (Cates et al.,1990). Withdrawal from

interpersonal relationships may also characterize an adolescent's response to loss (Osterweis et al, 1984); fears about not meeting social expectations of the peer group may increase reluctance to communicate feelings directly to others, further increasing isolation and straining important supportive relationships.

AIDS and Ethnicity

Gender and ethnic differences in families' adaptation to coping with AIDS are likely to be dramatic.

Gender and ethnicity are highly salient variables which will impact upon the adolescent's and the family's response to AIDS, the manner in which they cope, and their reaction to intervention. Ethnicity influences basic definitions of family and family life cycle, determines which events mark important transitions, and may determine use of and attitudes toward the health care system (McGoldrick,Pearce & Giordano, 1982). Ethnicity may account for differences in the way individuals experience pain, label symptoms and communicate about their illness (McGoldrick et al, 1982). Ethnicity also shapes values and attitudes that contribute to children's socialization, influencing coping style and interpersonal problem solving (Rotheram, 1988; Rotheram & Phinney, 1987). Communication style, orientation towards the group and relationship to authority (Rotheram & Phinney,

1987) are all ethnically-influenced aspects of an individual's style of coping with stress and conflict.

There has been a lack of attention to ethnic and gender differences in the psychiatric research on AIDS (Nakjima & Rubin, 1991). There has been one article dealing with group work with people with AIDS and the specific cultural and individual needs which must be respected in the design and implementation of services. (Child and Getzel, 1990). Another article on AIDS prevention with Black and Hispanic drug users (Schilling et al., 1989) suggests that group approaches might increase the efficacy of interventions that need information dissemination. It is recommended that racially mixed groups have at least two members of each racial-ethnic group to avoid scape-goating and increase validation.

Integral to the person with AIDS and their family is the delivery of medical and social services. Particularly those which are hospital-based have been described as insensitive to the needs of Black and Hispanic clients. Most professionals are taught and required to perform using Anglo-American values. Other cultures' values are neither taught nor honored. As a result, the expectation that pregnant adolescents with HIV can be counselled in a non-directive way or just given the "facts" to make their own choices is highly suspect and unlikely.

Hurst and Zambrana (1980) make keen observations from

their work with East Harlem women who must deal with a health care system designed and operated by white affluent males. These authors point to the many ways their clients cannot control the system, but exert some control by "shopping around" for health care. They also point out the despicable attitudes of some providers who believe women deserve pain and should be "knocked out" to keep them quiet.

Ultimately, consumers or clients vote with their feet and stop listening to or communicating with those whom they know are judging and discrediting them. This problem gets labelled one of non-compliance by the medical provider and insensitivity by the client.

This is often the experience of mothers with AIDS and the experience that their adolescent children observe as they escort them to medical appointments. Cultural insensitivity in the medical and social support networks makes the potential treatment of adolescents extremely difficult since trust is a major factor in their receipt or rejection of services. Harlon Dalton (1991) points out that "there is a profound need to re-orient the public health enterprise so that it can succeed in a multicultural society". His article suggests that Blacks' impulse to disown the disease AIDS is based on the problematic relationship between the Black community and the larger society. He asks how the Black community sees its own health needs and how AIDS compares to other concerns.

The current medical system and clinical drug trials often provide permanent barriers to care. This is true especially if fate, idealism and spirituality are or become the consumer's modus operandi. It is not that the patient is making "informed choices". It is that the institutions and people providing the information are ignorant of the process and the culturally biased messages they are delivering. A client may not be able to hear the choices because of the context within which they are being presented.

In Cross Cultural Counseling: A Guide for Nutrition and Health Counselors, Anglo American values are compared with other culture's values. Values such as time, change, equality, self-help, competition, materialism and informality may be considered American when they are really Anglo-American. Values such as fate, tradition, hierarchy, group welfare, cooperation, formality and spiritualism are often held by other American cultures. When services are provided by professionals who are not aware of cultural differences, the chances for misunderstanding and poor care are significantly increased. This has been the case for minority men and women receiving care for AIDS. Women have the added difficulties associated with sexism--particularly concerning child bearing issues.

As an ethnic group, Hispanics are over-represented in reported cases of AIDS. In families with AIDS in New York

City, they represent 49% of all cases--with Blacks having 42% and Whites 9%. Marin (1989) suggests that prevention campaigns for Hispanics must include Hispanic cultural values as simpatico, familialism, personalismo and power distance if they are going to be perceived as relevant. Posters informing men about condoms were ineffective because men did not want to be seen reading them. Newspapers with similar messages were more useful. In addition, since many Hispanic men who have sex with men do not identify as homosexual, messages about prevention cannot have a pro-gay theme. The ramifications for adolescents are very important since Hispanic boys are often terrified while exploring sexuality and young girls are often dating Hispanic men twice their age. The prevention and treatment modalities must take into account these factors.

When it comes to African-American children, there are some conflicting findings regarding their self-concept. Barnes (1972) says African-American children have incomplete self-image, negative self-image and preference for white, and rejection of and expressed hostility toward one's own group. Other researchers do not agree with this research and have written on the positive self-concept of Afro-American children (Powell and Fuller, 1970). In studying families with AIDS, it is unclear how self-image is affected by being poor, having a stigmatized illness and living within a racist society. Still, strategies for prevention

and service delivery must try to strengthen and support the family and child wherever they are on the continuum. As Powell (1983) states: " Afro-Americans have survived a harsh system of slavery, repression and racism. Although there have been casualties, there have been many more survivors, achievers, and victors". AIDS is one more dramatic example of this and the adolescents in families with AIDS have another significant challenge ahead.

Coping with Serious Life Events

Research describing coping with other serious life events (substance abuse, chronic illness, coping with early death) suggests that families and adolescents will experience significant adjustment problems. Although research pertaining to adolescents' reactions to loss and death, particularly death from AIDS, is sparse, some literature on maternal loss in childhood indicates that bereaved children are at increased risk for depression (Bifulco, Brown & Harris, 1987), agoraphobia and panic (Tweed, Schoenbach, George & Blazer, 1989), conduct disturbance and suicide (Chiefetz, Stavrakakis & Lester, 1989). They are also more likely than their peers to experience academic difficulty, decreased self-esteem and somatic complaints (McKeever, 1983). Diminished communication leads to what Turk (1964) described as a "web

of silence".

McKeever also emphasizes the degree of role differentiation and communication style as important variables in a family's ability to cope with chronic illness. Anticipatory grief, characterized by affective disturbance and behavioral disruptions, is often an isolated experience for youth in families with an ill or dying parent, as there is little energy for that parent to expend in caring for other family members (Rosenheim & Reicher, 1986). As with other chronic illnesses, individuals with AIDS are likely to exhibit helplessness, threatening and hostile behavior, and become increasingly demanding and argumentative (Cates et. al.,1990). Thus, the stress generated by medical illness is frequently compounded by family discord, and the families' established coping patterns are strained. Families coping with pre-existing and long-standing stressors such as poverty, substance abuse and violence may be at increased risk. Both the frequency and perceived negative impact of life events affect both behavioral adjustment and mental health among adults (Holahan & Moos, 1981) and inner-city adolescents (Rotheram-Borus, Rosario & Koopman, in press). Additionally, in a study of long-term stress as a consequence of trauma, subjective impact of trauma and related financial and employment concerns were found to be more predictive of psychosocial outcome than medical variables were (Landsman,

Baum, Arnkoff et.al. 1990). Adolescents may be especially vulnerable to these stressors. It has been noted that separations, divorces, deaths and severe family discord have all been implicated in increased risk for suicide (Hirshfield & Blumenthal, 1986). Moreover, suicide is just one of a cluster of behaviors adolescents with adjustment difficulties exhibit; depression, trouble at school, trouble with the law, and unprotected sexual intercourse are frequently present as well (Ensminger, 1987). The likelihood of a complicated grief reaction in those surviving an AIDS death is compounded for individuals whose initial response to diagnosis is marked by psychosocial distress and inadequate social support.

The conspiracy of silence described in <u>They Never Want To Tell You: Children Talk About Cancer</u> (Bearison, 1991) is very true for AIDS as well. The conspiracy by which each person is pretending to protect the other suppresses the fear and discomfort which needs to be felt and expressed by the ill patient and other family members.

Children tell their stories in this book and repeat how they must tell each of their friends that they do not have to fear catching their cancer. AIDS is not the only illness that people fear catching nor the only illness that too often comes with blame. Bearison describes how parents and children blame themselves for their cancer in striving to answer the question, why me? On a practical level, secrets

can impede understanding, foster isolation, prevent access to services and increase stigma. (Abramson, 1990). This makes coping with serious life events an even greater challenge.

Children and Grief Reactions

"Surprisingly little is known of the short-term effects on the child caused by the loss of a parent through death". (Wolkind and Rutter, 1985). Whereas many children do not show manifestations of grief, time seems to help them master the loss in some way.

The effect of AIDS on adolescents must be based upon the developmental processes of adjustment to illness and bereavement as they impact individual and family coping strategies.

While many of the tasks faced by individuals and families coping with illness and death are universal (Moos, 1984), there are illness-specific tasks as well. Moreover, the needs of individuals and families will change over the course of the illness (Corby & Wilson, 1989). AIDS, a gradual, progressive and incapacitating illness, is unique in its association with groups highly stigmatized by society-- homosexuals and IV drug users (Wiener & Septimus; Frierson et al, 1987). The stigma associated with the disease is a significant factor influencing coping in

different phases of the illness (Schneider et al,1991), and results in increased social stress related to issues of disclosure for adolescents (Sinclair, 1990) and their families (Cates et al.,1990.) Fears about the potential ramifications of disclosure lead persons living with AIDS and their families to become increasingly isolated and cut off from social support networks and other important resources (Cates et al, 1991). Doka (1990) refers to AIDS as a "disenfranchisizing death" because of the fear and panic it generates. This can result in isolated survivors who do all their grieving alone.

Although many professionals believe that talking about problems is healthy, secrecy may need to be respected as the best way for individuals or families with AIDS to cope. (Grief and Porembske, 1989). AIDS often creates the opportunity for family members to face issues that were taboo previously. (Dane, 1991).

Greenberg (1975) discusses the importance of open communication and shared expression of feelings in a family system in order for a child's grief work to be accomplished. In her therapeutic work, the cries of 'nobody would ever talk about it' ring out. Children also need to know that adults have many unanswered questions about death. Greenberg states: "Children can be helped to work through their unresolved grief feelings by appropriate empathic communication. Positive outcomes are then characterized by

future-oriented children with enhanced self-esteem who have developed a sense of their own power to survive and grow." For children and parents dealing with AIDS in a secretive environment, this is a difficult process.

Greenly and Moynihan (1983) have developed areas of psychological knowledge which need to be conveyed to surviving parents who they recommend be approached as colleagues. They have found that the collaboration of professionals and surviving parents creates a positive focus on their strengths. This concept of focusing on the strengths of those being served is the theme of Gray and Nybell (1990) in serving African-American families. The "nondeficit" approach must be used. This point is echoed by Schorr (1990) who suggests that in successful programs staff work in a setting that allows them to provide services "respectively, ungrudgingly, and collaboratively."

Greenly and Moynihan also discuss work with adolescents who are trying to deal with loss at the same time they are reexperiencing feelings around separation and individuation. Sometimes adolescents deal with this by overidealizing the parent. Their defensive splitting of the negative aspect of ambivalence may result in hostility toward surviving adults. They may blame survivors (including themselves) for the death and may even consciously wish they were that person instead. This may result in enormous conflict with the surviving parent and/or guardian.

Anna Freud (1960) describes mourning by saying: " The process of mourning taken in its analytic sense means to us the individual's effort to accept a fact in the external world (the loss of the cathected object) and to effect corresponding changes in the inner world (withdrawal of libido from the lost object, identification with the lost object)". Moses Laufer (1966) raises some difficult questions concerning mourning and adolescent development. These include; "What happens if the adolescent loses, in reality, the object from whom he is trying to free himself? What internal factors play the most important part in determining the outcome? How does the failure of mourning in adolescence manifest itself in adulthood?" When adult patients are in analysis, the possible consequences of unresolved mourning are affectlessness, depression, compulsive weeping and shallowness of object relationship. (Deutsh, 1937).

Craig Podell (1989) discusses adolescent mourning resulting from the sudden death of a peer. Although his work does not include AIDS or parents, his statements about the way adolescents mourn are very important. Survivor guilt is described and has serious implications for AIDS deaths where the child often believes the parent or sibling would not have died if the adolescent had been home that day or intervened in some way.

A Child's Parent Dies: Studies in Childhood Bereavement (Furman, 1974) discusses in great detail the differences between adult and child bereavement. Whereas a child tends to invest all his/her feelings in the parents, an adult usually distributes love among several meaningful relationships. This makes a loss more tolerable for an adult than the child. This book with its extensive bibliography focuses on surviving parents and their children. What makes AIDS different is that almost all the families start out as single parent households so that the loss of a parent almost always results in the child being a full orphan. Furman points out that having parent substitutes (such as a grandparent) does not spare the child the pain and distress of mourning. But the support and care of others does help the child to deal with the pain. Furman also states: "Mourning is a difficult task at best. When it has to be undertaken under anxiety-arousing external conditions it becomes almost impossible." The conditions under which well adolescents in New York City experience the death of their parents to AIDS is fraught with chaos, stigma, racism, and poverty. The professional literature tells us how difficult it is for all children to mourn. Doka (1990) describes how much grief is affected by social norms which define how one should and should not grieve. Listening to others provide condolence messages is a clear and often painful way to hear the social instructions given

by friends and relatives. When the social rules are very different from one's personal bereavement experience, the conflict is complicated and troubling.

There is no question that a child's need for love, support and care is enormous following the death of a parent. (Siegel et al., 1990). The proposed study is about listening to the adolescents and their parents or guardians report on what might have helped and how professionals can be of more assistance to others like them in the future. "Researchers have not proposed and tested models of the processes through which parental death leads to increased mental health problems in children." (West et al., 1991).

Conclusion

The literature associated with AIDS, adolescents, ethnicity, serious life events, and grief reactions is helpful in setting the context for the study of the needs of well adolescents in families with AIDS. Books and journals in social work, medicine, sociology, and psychoanalysis were reviewed in order to learn about previous writing which would inform this study.

Perhaps because AIDS is relatively new or because it crosses so many disciplinary categories, the literature in interdisciplinary journals such as Orthopsychiatry and Families in Society was the most beneficial.

The literature on death and dying was significant in

depth, but not in relevance. Almost all the studies in this area presumed a three to five day a week psychoanalytic model which most people with AIDS and their families neither have the time nor the resources to utilize. The information about mourning almost always related to an individual's struggle and rarely mentioned the family. When the family was included, there was always a mother, father and a few children. So the child's mourning was most often done with the assistance of a surviving live-in parent.

Families with AIDS challenge us to adapt what we know and create new interventions for future service.

CHAPTER TWO

METHODOLOGY

Introduction

In 1990, the Planning Unit of the New York City Human Resources Administration Division of AIDS Services applied for and received funding from the National Institute of Mental Health to conduct an assessment of the mental health needs of well adolescents in families with AIDS. (Contract # 279492). This study will lead to an increased understanding of the important factors in planning intervention activities which will support these adolescents and others like them in the future.

Because I had been known to administrators, supervisors and case managers within the Division for three years, the role of student/researcher was accepted quite readily. The planning role had provided an opportunity to study various facets of the program and make recommendations for change. Since the original interest in well adolescents came from the case managers, my role was one of receptor rather than initiator.

Access to clients and data was not a problem because the case managers and their supervisors were supportive of the project. The Division of AIDS Services provided an excellent opportunity to mount a study which could give

immediate information and recognition to the institution. The city and department structure are described in order to detail the full context of the study. In the case of this study, the bureaucratic structure was clear and helpful. The study demanded the full cooperation of the Family Case Management Unit, headed by an interested and extremely supportive social worker.

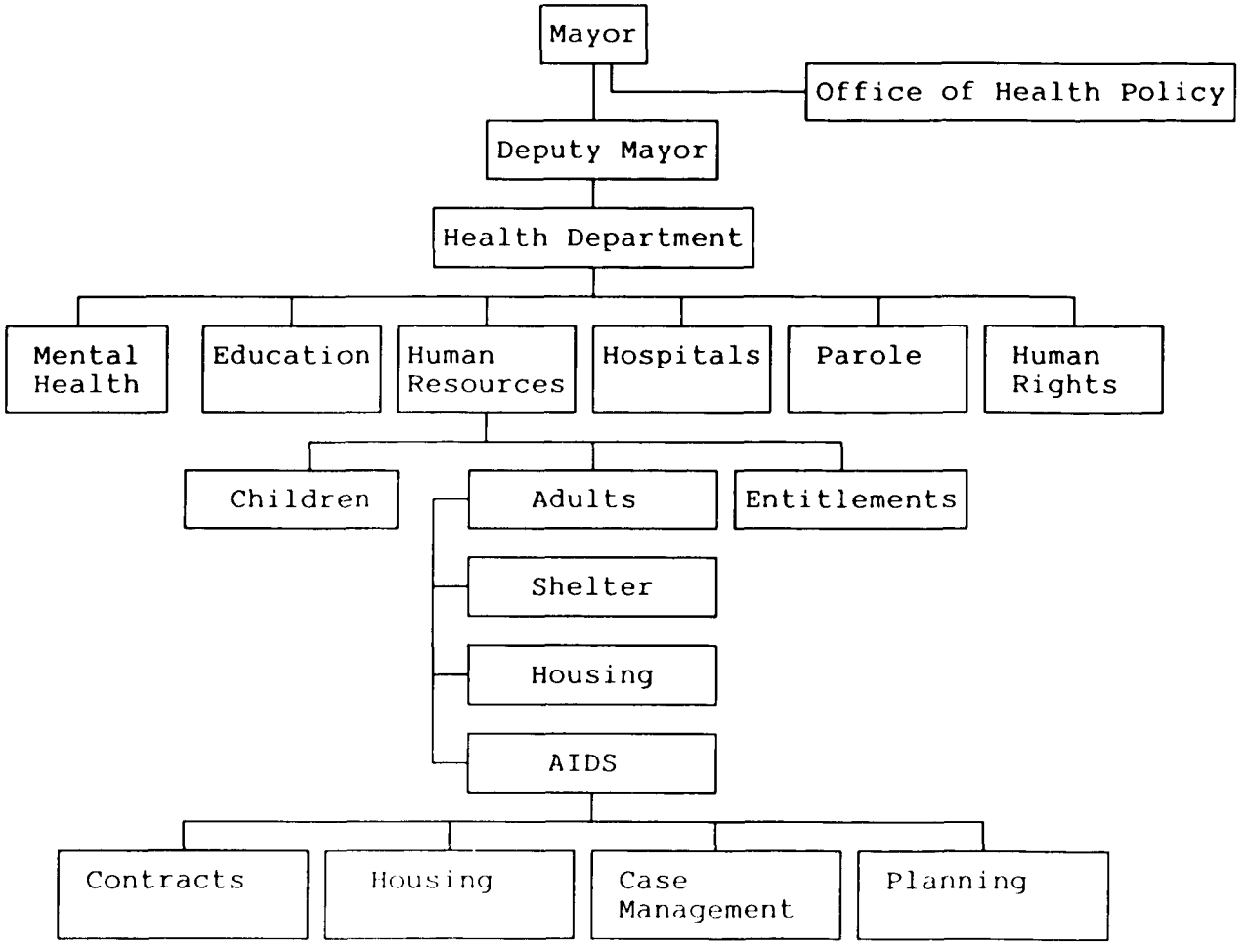
In this chapter, the selection of standardized measures for the quantitative data will be detailed as well as the design of qualitative instruments. I will describe my role of principal investigator and the part played by two assistants. A section addressing the confidentiality issues related to HIV and families will be outlined as well as the important issue of client consent.

Description of the Setting

This study of the mental health needs of well adolescents in families with AIDS was undertaken at the NYC Human Resources Administration's Division of AIDS Services (DAS). The project was conducted during 1991--a period in the AIDS epidemic when drug users and families began the second major wave of the epidemic. Families make up about one-sixth of the total AIDS caseload and are expected to grow more quickly than other populations affected by the epidemic.

Table 1

Organizational Structure for Dealing with AIDS



The Mayor's Office of Health Policy is responsible for the coordination of health services by multiple agencies. The city government has three primary agencies with the responsibility for dealing with health issues. The three agencies are the Department of Health, the Health and Hospitals Corporation, and the Human Resources Administration. The mission of the Health Department is to protect the health of the public by conducting surveillance studies on medical issues. They are keenly involved in health education and public awareness of prevention strategies. The Health and Hospitals Corporation directly operates 17 city hospitals which predominately serve Medicaid, underinsured and uninsured patients. The Human Resources Administration is responsible for providing social services to the city's indigent population.

AIDS demonstrates the importance of agencies working together in order to protect the health of the city's population as a whole as well as the complex and specific needs of clients who are ill. The Mayor's office of Health Policy worked with the Health Department which was named the lead AIDS agency to coordinate the city's response to the devastating disease. Together the Mayor's Office and Health Department created the Interagency AIDS Task Force which included 7 agencies. (Health, Hospitals, Human Resources, Discrimination, Education, Parole, and Mental Health.) These agencies met monthly to devise a 5-year plan and to

make decisions about the organization of health and social services.

The Human Resources Administration (HRA)

The Human Resources Administration is the umbrella agency responsible for the city's social services which are defined broadly and include entitlements such as public assistance and Medicaid, home care including nursing, child welfare including adoption and foster care, and adult services including shelters, alternative housing and AIDS. Whereas the mission of the health department is to protect the public's health and prevent illness, HRA helps individual clients who need services once they are sick, disabled, unemployed or unable to care for themselves.

In 1985, the Mayor requested that the city's Human Resources Administration assume responsibility for providing specialized, out-of-hospital services to people with AIDS who were indigent or who had depleted their resources.

The Division of AIDS Services (DAS)

In response to this request, the Human Resources Administration established the Division of AIDS Services (DAS), now one of the country's largest programs providing case management services to people with AIDS (PWAs). The

mission of the division is to provide comprehensive and coordinated services to Medicaid eligible people with advanced HIV illness or AIDS.

When HRA's AIDS Case Management Unit began offering services in 1985, it was assisting fewer than 200 people with AIDS. By the end of 1991, the Division was serving 9245 Medicaid eligible people with AIDS or advanced HIV illness. 70% of the referrals came from hospitals where the patients were awaiting discharge. The remainder came from prisons and private physicians. Of the 9245 cases, 1516 (16%) were family cases. The Division currently serves approximately 73% of all adults with AIDS in the City.

Within DAS there are four subdivisions:

- The Contracts Unit maintains 30 contracts with community agencies for a range of services for DAS clients, including housing, meals, food pantries, personal counseling, and nutritional and drug treatment counseling.
- The Housing Placement Unit places homeless or inadequately housed DAS clients with AIDS in a range of settings, from congregate facilities to independent-living apartments.
- The Planning Unit conducts strategic planning, program development, training coordination, and relates to community-based agencies providing services in conjunction

with HRA. This study was done by the Planning Division in cooperation with the Case Management Unit. With over 9,000 active clients in December,1991 DAS currently serves more than 73% of the People With AIDS (PWAs) living in the City.

• The AIDS Case Management Unit (CMU) includes 315 Case Managers providing continuous, comprehensive case management services to 9,245 Medicaid-eligible people with AIDS or other advanced HIV illness. Within the CMU, there are special units for services to families with AIDS.

DAS Service Level Projections

Current projections for service levels through 1995 are intimidating. These projections devised by HRA's Division of AIDS Services Planning Unit in cooperation with the Mayor's Office of Management and Budget are shown in Tables 2, 3, and 4.

Table 2

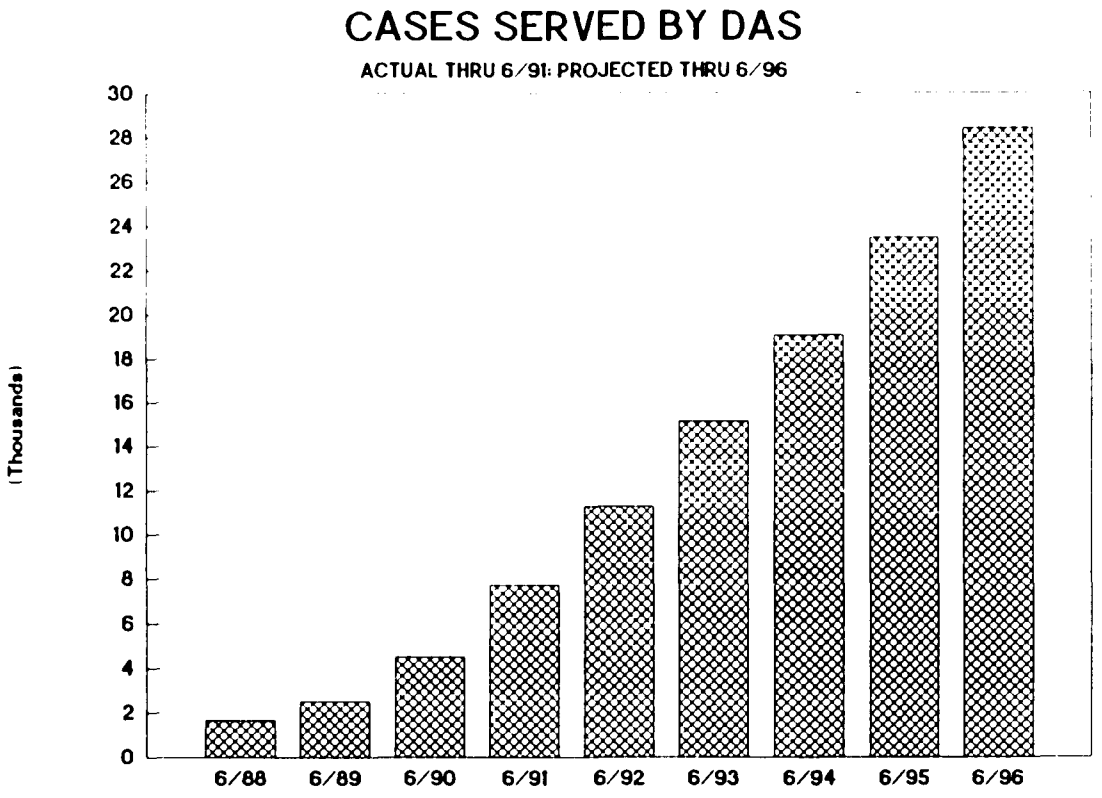


Table 2 demonstrates the dramatic growth in cases served by HRA's Division of AIDS Services from its inception in 1988 projected through 1996. The Division serves Medicaid eligible individuals and families with Advanced HIV illness or AIDS. Over 80% of the cases are full blown AIDS. Because of the significant growth in cases, the bureaucracy has had to answer needs for space and personnel - two of the most difficult commodities to address in a large urban organization. In addition, the constant doubling of the caseload within a two year period suggests the need to reorganize service delivery systems.

Table 3

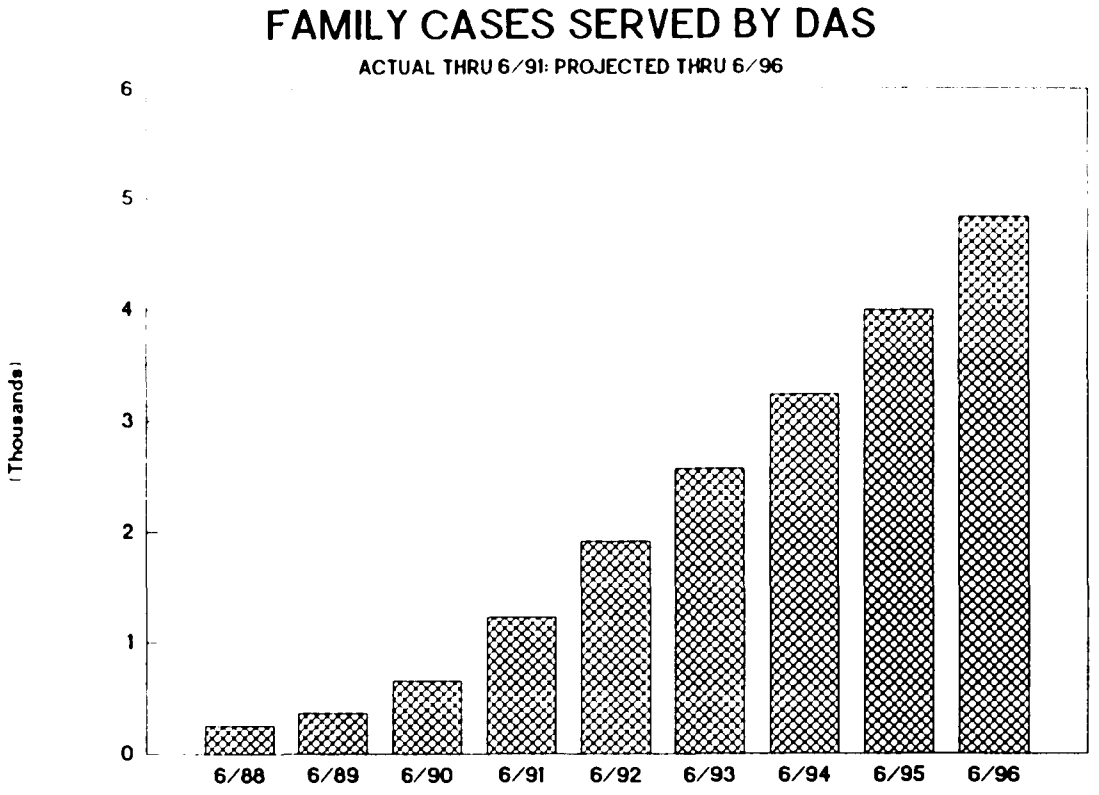


Table 3 confirms that the growth of families is similar to that of the total DAS caseload. Families are defined as a parent and child - one of whom has AIDS. Families average 3 members including the HIV infected person. Families require additional services to single cases because the children need special attention both during the illness and they need a custody plan for the future. Families have more complicated issues pertaining to disclosure. It is more difficult to conceal the diagnosis to members living in the same household. It is also harder to assess the effects of knowing and not knowing about the diagnosis on children.

Table 4

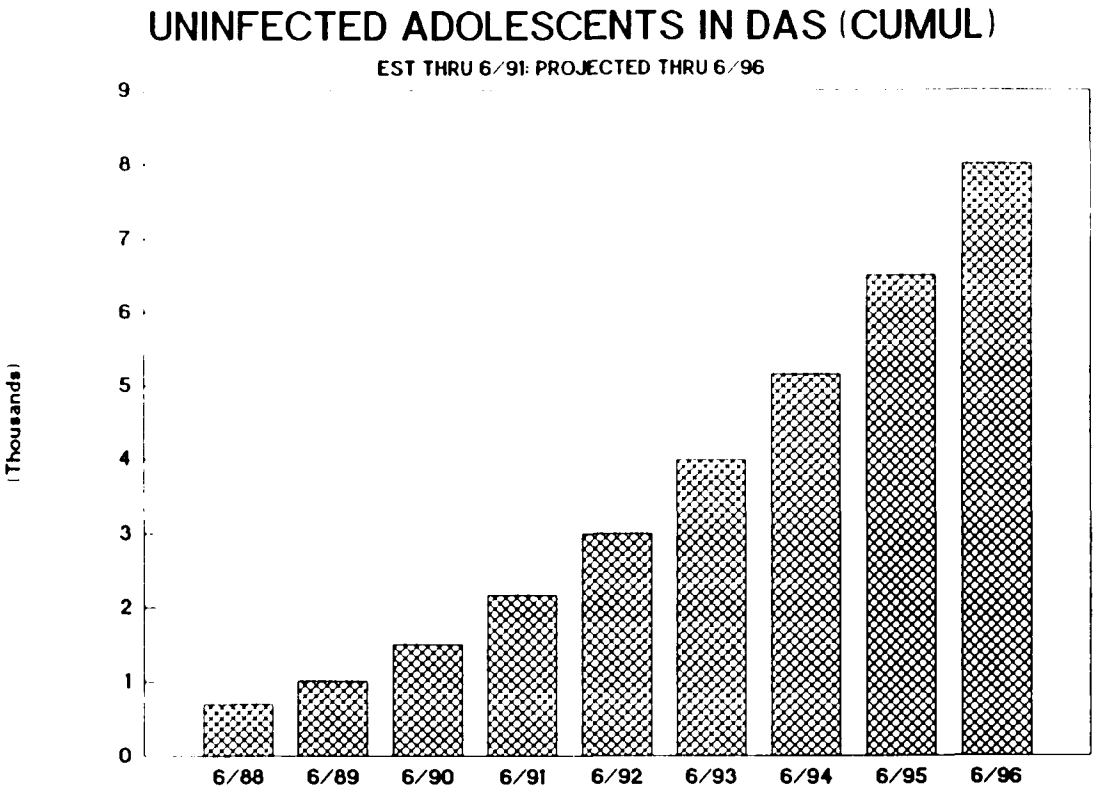


Table 4 describes the numbers of well or uninfected adolescents in families with AIDS. By 1996, there will be over 8,000 adolescents. This study points to the need for special services for this particularly vulnerable population. Their growth from less than 1,000 in 1988 to over 3,000 in 1992 points out how quickly this group is growing and the necessity of moving speedily to address their needs.

The Case Management Unit

The approach to case management for people with AIDS emphasizes a one-stop, comprehensive and continuous service, delivered in a coordinated and accessible manner. Without this consolidated service program, people with AIDS would need to go from office to office to obtain the same benefits. Instead, an AIDS Helpline, well-known by medical and social service providers, serves as the single point of entry for these services, whether for individuals or for families affected by AIDS. The Helpline conducts a telephone interview and clients, once accepted for service, are assigned a case manager who remains with the case from beginning to end. Referrals to the Helpline for AIDS case management services are regularly received from public and voluntary hospitals, correctional facilities, physicians, psychiatric hospitals, drug treatment programs and other community organizations.

The AIDS Case Management Unit provides a range of essential services to clients, including help in applying for entitlements (public assistance, food stamps, social security benefits, Medicaid) and arranging for home care. Clients also receive help in finding and/or paying for housing; HRA offers supplements to its clients with AIDS so that they can afford to remain in their apartments, even when they cannot work and their resources are limited.

As the number of clients with AIDS has increased, the make-up of that population has changed. Two years ago, most of the program's clients were gay men; today, while the numbers of gay men continue to increase, the population of people with AIDS has been dramatically expanded because of the increasing numbers of women and children who are HIV positive. This is reflected in the December, 1991 DAS caseload which includes 1516 families and 251 children. This is in contrast with the June, 1988 caseload which included 248 families and 36 children. For purposes of the AIDS Case Management Unit, "family" is defined as a household which includes a child and parent or guardian, at least one of whom is a person with AIDS.

The Family Unit

The Family Unit seeks to provide services to these increasing numbers of families--mostly single mothers and children--in which AIDS is present.

Table 5 illustrates the growing numbers of women and children with AIDS city-wide.

Table 5

Cumulative Cases of AIDS Reported in New York City

Data from New York City Department of Health
AIDS Surveillance Unit,
November 30, 1990 through December 31, 1991

November 1990:

	TOTAL	WOMEN	CHILDREN
City-wide	29,443	4,217	726
Bronx	4,648	1,058	227
Brooklyn	6,224	1,270	219
Manhattan	12,973	1,171	151
Queens	3,448	522	81

December 1991:

City-wide	36,574	5,631	862
Bronx	5,931	1,450	262
Brooklyn	7,795	1,688	267
Manhattan	15,623	1,501	180
Queens	4,427	731	100

Over 90% of the families are headed by single mothers. Whereas some of these women have male friends, the men rarely partake in child rearing responsibilities. Many of the men have already died of AIDS. It is important to note that the children in each of these households most often have different fathers whom they rarely or never see. Of the family cases, 49% are Latino, 42% are African-American and 9% are white. The mothers with AIDS are overwhelmingly minority, low income women who are dealing with their illness and raising a family

at the same time.

The Family Project is a special program within the AIDS Case Management Unit, designed to enable a household affected by AIDS to remain together as long as possible. Like the program of case management for individuals with AIDS, the Family and Children's AIDS Project emphasizes a one-stop, multi-service approach, but also includes more intensive family counseling and social support. The unit is unique in its holistic approach, dealing with affected families as a single unit and therefore preventing fragmentation of services and support.

The Family Project began as a pilot program in April, 1988. The award of a three-year federal grant through the Health Resources and Services Administration and the State AIDS Consortium has enabled expansion of the program. Currently the program is operating at seven sites where the greatest number of family cases exists. Each unit consists of a social worker/supervisor, 5 case managers, a part-time nurse, and a part-time child welfare specialist. The case managers offer direct and ongoing client contact. Nurses, rotating among the sites, monitor the health of family members, offer risk-reduction guidance, assess home care needs, and make appropriate medical referrals. The child welfare specialist assists in maintaining family unity and, when necessary, plans for the permanent placement of children in families who cannot remain together.

The impact of AIDS and other HIV-related illnesses on families is staggering. Each family affected by AIDS is unique unto itself, but all such families are especially vulnerable and need concentrated and comprehensive services in order to preserve the family's strength. Families need assistance to help compensate for their lack of resources, to help ill family members who require increasing levels of care, to gain knowledge so that HIV will not be spread further through unprotected sex, intravenous drug use or during pregnancy, and to cope with the illness and death of parents and children.

With this in mind, the Family Project offers a number of specialized services to families. These include family counseling, continuous health monitoring, referrals for medical attention and risk-reduction education to prevent the further spread of HIV infection. The Project also coordinates with other HRA agencies to provide necessary services. For example, foster care services are provided and are available on a 24-hour, seven-day-a-week basis to assist families which are overwhelmed by the burden of AIDS and unable to care for their children under those circumstances.

Finally, the case manager must assess when to close a family case - that is, when resolution of various key issues has taken place. Closure is appropriate when survivors have been assisted through the burial and bereavement process, financial entitlements have been transferred, and all custody

issues have been resolved. All family members are therefore served and supported throughout the illness, as well as through an adjustment period following the client's death.

This wide range of services can provide the critical difference which enables a family to remain together. One case involving a grandmother caring for three children with AIDS illustrates the kinds of services needed. The grandmother had recently lost her daughter to AIDS. All three of her daughter's children were ill with HIV-related diseases. The Family Project arranged for home care so that the grandmother would be able to continue to care for her grandchildren. The program also ensured that the family would receive all the financial benefits to which it was entitled in order to meet household expenses.

Another example involved a mother with AIDS whose three-year-old son was also ill with HIV-related infections. Following her hospitalization for AIDS-related complications, the mother was released back to her rented room. The room was dirty and the laundry piled high; the mother, now losing her vision, was unable to perform basic household duties. The Family and Children's AIDS Case Management Project arranged for daily home care for the mother, as well as homemaking services for her son. The home attendant has been a supportive and caring presence, enabling the mother to maintain a close relationship with her son. The mother now refers to the attendant as "my eyes."

DAS's Family AIDS Case Management Program has received national attention. In a 1990 textbook, Social Services for Children, Youth and Families, its authors, McGowan and Kamerman noted:

> Despite the difficult and tragic nature of many of these clients' lives, this is a program that can be considered successful. Keen sensitivity to the needs of clients combined with an administrative structure that allows workers to meet those needs would seem to the key factors making this a successful program.

DAS's Family Project was a semifinalist in the 1991 Innovations in State and Local Government Awards Program sponsored by the Ford Foundation and Harvard University. The Family AIDS Case Management Project is more than just the sum of all these services. Family Program case managers--all of whom requested these specialized positions--offer a human touch, listening to their clients, counseling and caring for them and their loved ones. For PWAs who have lost contact with extended family members or friends, the case manager becomes a friend and confidante, sometimes the homebound or hospitalized client's only contact with the outside world. Because an AIDS case manager spends so much time with each client, these case managers service fewer clients than do other social service workers.

In 1990 the family case managers began to recognize and acknowledge the special needs of adolescents within families. More and more case managers reported that parents were discussing problems related to controlling their adolescent

children. Case managers reported to the Planning Unit that the problem of well adolescents in families with AIDS needed further study.

Beginning the Study

Two major groups who created the study were the research team and the planning committee.

The Research Team

The planning unit's primary responsibility is to identify the special needs of people with AIDS and to design programs which can be implemented within the Division. The planning unit is currently conducting a national family AIDS demonstration program funded for four years by the Health Resources and Services Administration (HRSA).

On a regular basis, the Planning Department conducts focus groups with case managers to learn more about current and anticipated problems in service delivery. In 1990, case managers gave anecdotal accounts of parents' difficulties in dealing with adolescents. In June, 1990, a computer run was able to assess the total number of adolescents affected by the illness of a parent. There were 639 uninfected adolescents in 410 families with AIDS. Table 6 shows the composition of adolescents in families.

Table 6

Composition of DAS Family Clients

Family Composition	# cases	percent
Families with 1 adolescent	109	52
Families with more than 1	161	39
Families with more that 2	40	9
Total families with adolescents	410	100

Most families have at least one other sibling in addition to the adolescent.

Because of personal accounts from case managers of the quality of the problem and computer accounts of the quantity of the problem, it was deemed important to study the issue of well youth in families with AIDS more thoroughly.

While most of these youth are not themselves infected with HIV, they are, nevertheless, seriously affected by the illness and death of parents and siblings. For the most part, these children have been overlooked by programs designed to serve those most affected by AIDS. This new assessment effort would provide information about these youth which would lead to the design of critical emotional support, linkage to community services, and prevention education.

Recognizing the special needs of well adolescents in

families with Aids as an important and growing area of concern, the Planning Unit applied to the National Institute of Mental Health (NIMH) for funds to conduct an exploratory study. An NIMH contract (#279492) to conduct the study was awarded in September, 1990, for a one year period.

The principal investigator for this study is the Director of Planning of the Division of AIDS Services. Grants from NIMH and HRSA provide two staff positions, making up a team of three. One of the two assistants is bilingual and has a Masters of Social Work degree. He was able to conduct interviews in Spanish and do clinical follow-up with clients. Another assistant has a joint Masters of Public Health and Public Administration. She was able to conduct interviews and survey available research instruments that would inform this study.

The Planning Committee

To design the study, a weekly planning committee met to flesh out the goals, issues, problems, and logistics. This group was made up of the principal investigator, the two planning assistants, the director of the family case management unit, two academicians, a family social work supervisor and a family case worker. The group met twice with the NIMH program monitor who contributed important information on other related studies underway.

The grant from the National Institute of Mental Health was a conducted through the cooperations between the planning unit and family program. The planning committee decided that all clients selected for the study would be currently served by the Division or have been a client within the last six months. The intent of the study is to interview parents and adolescents while they are clients of the Division to find out how they are doing and to interview guardians and adolescents after they leave the Division to ask them about the transition away from the unit and their current needs.

Brooklyn was selected as the target site for this exploratory research because it has the greatest number of families served and the largest ethnic diversity. All supervisors and case managers received at least 6 hours of training which outlined the purpose and methods of the study and answered any questions and/or concerns. This training emphasized that client participation in the study was totally voluntary and should not affect the delivery of entitlements and services in any way.

Assessment staff had full access to case files within the Division and occasionally reviewed files to determine client and worker needs. For the purpose of this study, assessment staff reviewed all family cases in Brooklyn to ascertain if there were adolescents living in the family. (Supervisors and case managers also helped to sort files).

It was decided that 40 families would be interviewed. Of the families interviewed, 20 families would be composed of a parent with AIDS and their adolescent child(ren). In 20 additional families, the parent would have died in the last year and the interviews would be conducted with the new guardian and the adolescent(s).

Inclusion criteria for the study included:

a) HRA AIDS Services client now or in the past 6 months

b) be in a family with AIDS now or in the last 6 months

c) have adolescent children living in the family

d) be a resident of Brooklyn

Qualitative and Quantitative Methods

It was clear from the planning stage of this study that the information being sought was not available in case records and had not been gathered by researchers. Instead, it was in the hearts and minds of clients. Since we wanted to know how problems were experienced by adolescents in families with AIDS, we decided that the adolescents and the parent or guardian were the best informants.

In order to elicit this information, it was decided that qualitative methodologies would serve the study by

helping to describe the clients' reality and generate rather than test hypotheses (Epstein, 1985). This method would provide flexibility and openness and give the client an opportunity to open doors of inquiry. The qualitative method would be suitable because the study was being conducted in a natural setting (the client's home), would use the researcher as the chief "instrument" in data gathering and analysis, would elicit data from the perspective of those being studied, would be focusing more on social processes than on outcomes, and would be using an inductive approach to data analysis. These study objectives were based on concepts taken from Bauman (1972), Reichart and Cook (1979) and Bogdan and Taylor (1975) in their descriptions of qualitative research.

Pilot testing of the first open ended questionnaire quickly demonstrated that obtaining accurate family information was considerably more complicated than researchers had anticipated. A new method was needed to both understand and document the family structure. A lecture and book on genograms assisted the interviewers in organizing the collection of data related to family structure and relationships. It was decided that each interview would begin with the creation of a genogram (McGoldrick, & Gerson, 1985) by the adult and adolescent being interviewed. The genogram was useful for finding patterns within the family system and in documenting

important changes in relationships between family members.

In addition to providing a concise way of describing family relationships, the process of creating the genogram allowed the interviewer and client to establish a rapport essential for the successful completion of the remainder of the interview. Working with parents or guardians to see the larger picture often allowed for "reframing and normalization" of emotion laden topics. It also alerted the interviewer to those areas of family history that were likely to require the most sensitivity and care during discussion.

After conducting several interviews, it also became clear that the original qualitative, open-ended questionnaire format would be greatly enhanced by the addition of quantitative pre-tested instruments. The interviewers questioned whether the adolescents' scores in such areas as anxiety and depression were within norms. How different were these children in the way they handled stress and coping? Thus, it was our hope that the administration of widely used, scientifically validated instruments would allow us to compare the youth in our sample with youth in other communities around the country.

Identifying scientifically validated instruments appropriate for use in families with AIDS was extremely difficult because most family research instruments have been developed for use with white, middle class, "intact"

families. Intact in this case is defined as a mother and father, married and living together, in the same household with their children, who are free of existing psychopathology (Siegel, 1990). Few families with AIDS are intact by this definition. As indicated earlier, the majority of families interviewed for this study were single parent, female-headed minority households. In the few families with two adults present, one parent was usually the step-parent of all but the youngest children in the household.

Cultural and class biases were also apparent when considering pre-tested survey instruments. For instance, one measure of stressful life events included questions on the loss of car privileges or parental job change as indicators of stress. Not surprisingly, none of the teens in Medicaid eligible families with AIDS have cars and most adults are unemployed.

Based on such instruments, how could we tell if the adolescent mental health needs were related to the loss of a family member with AIDS or to many other factors such as poverty, drugs and racism in their lives? Were the needs of these adolescents significantly different from adolescents throughout the country? Were their conditions pathological? These questions could not be answered with available instruments, However, knowing whether or not the study adolescents scored outside of national norms might be

helpful in the design of future interventions.

Although this study would not be able to definitively answer all the foregoing questions, it was decided that using selective quantitative measures would help to address the query of how these adolescents scored on widely used instruments for such measures as self-esteem, anxiety, and coping skills.

The combination of qualitative and quantitative methods would provide more complete information about these families than either approach could elicit on its own. It was thought that using both methods would give the researchers the close-up and wide-angle lenses that together would provide a more accurate and rich, comprehensive picture of the respondents' lives. Since there is very little guidance available about how to combine these two approaches, (Schofield and Anderson, 1987), we were aware of the challenge it represented.

Recruitment of Subjects

Researchers reviewed all family cases in Brooklyn to ascertain if there were adolescents living in the family. A letter was sent to clients who met the inclusion criteria inviting them to participate by speaking to assessment staff about their family's experience of having someone ill. (Appendix 1). The word AIDS was not mentioned in the letter

or on the letterhead.

Even though all assessors knew and were entitled to know the HIV and health status of clients, it was very important to protect the family's confidentiality from outsiders--should the letter get opened, and from household family members who were not privy to the HIV status of one another.

Clients had the opportunity to call the assessment staff directly to convey their decision or researchers followed up by phone to learn of their decision. If clients called their case manager, he/she took a message and notified assessment staff. If clients declined participation, they were thanked for their time.

Clients wanting to participate selected a meeting time and place convenient to them. Most interviews took place in the clients' homes in the late afternoon or on weekends. Families were contacted on the day of the interview to reconfirm their availability.

To thank clients for their participation, families were given movie vouchers for all household members. They could use these tickets at any time in selected theaters throughout New York City. Clients were informed about these tickets in the invitation letter (Appendix 1).

Consent and Confidentiality

Minors and people with AIDS were both involved in this exploratory study. The parent/guardian gave permission for themselves and their minor(s) to participate. This permission was given in person and in writing. (Appendix 2). In addition, the minor(s) also gave permission in person and in writing. Any participant could stop the interview at any time. If a parent/guardian preferred, his/her own interview was separate from that of the minor and permission to interview the minor was contingent on the experience of the parent/guardian.

Precautionary steps taken to insure the protection of human subjects included an understanding that bodily harm to self or others revealed during the interview would require reporting as outlined in the consent form.

There were limits to confidentiality. Child abuse has mandatory reporting requirements.

Precautions were taken to safeguard identifiable records. Only the three researchers had access to the data which is kept in a locked file cabinet. Names will be permanently removed at the completion of the data analysis.

The researchers knew that a family member has/had AIDS because we work within the Division of AIDS Services and have legal and ethical rights to review client files. AIDS was never mentioned in the interview until the parent,

guardian or adolescent brought it up. Interviews were conducted with everyone knowing that the purpose of the assessment was to better understand the needs of well adolescents in families where there is/was a serious illness.

All terminal and devastating illnesses such as AIDS involve ongoing issues of denial and disclosure. These deeply personal processes were respected by the researchers. All interviews were conducted individually and privately. When there were 2 adolescents in the home, two assessors were used.

AIDS was not mentioned by the assessor in order to help the client. It was understood that during interviews, unexpected things could happen. It was anticipated that some adults would ask if the assessor knew they had AIDS. All such questions from adults were handled directly and honestly. It was anticipated that an adolescent might ask the assessor if the family member has/had AIDS. This adolescent would be asked to refer that question to the parent or guardian. (This situation did not materialize).

Whereas issues such as disclosure, denial, and HIV discrimination were of great interest to the assessors, these issues were only discussed at the clients' initiation.

Client Follow-up

From the inception of the study, a major concern of the principal investigator was client follow-up. Families with AIDS are vulnerable subjects to study. Their lives are short, complicated, complex and often overwhelming. It was essential for the integrity of the study that these clients gain something from the experience. It was a great fear that any research had the potential to be harmful. The terminal, episodic, and stigmatic nature of the illness is crushing to clients, family and professionals.

Safeguards were ,therefore, put into place. Clients who were ambivalent about participating were not encouraged to do so. All participants would be given movie tickets so that family members could experience a few recreational outings at their own convenience. A bilingual, clinical social worker was hired full time to do follow-up for forty families. If through detailed questioning, a family began to deal with a new issue, it was essential that a trained professional be available immediately upon request to follow-up in the home of the client. If the researchers discovered a family out of control or in danger, not only did it have to be reported, but we wanted to provide our own direct care. There was a case where researchers entered into a household in a state of chaos. The interviewers assessed that the children were at risk and immediately

reported this case to the Child Welfare Administration. The interviewers stayed with the family until other workers arrived. After extensive case conferences, the family was re-stabilized. Every family interviewed was asked if they needed or wanted additional services. The goal of the follow-up worker was to see the client in their home for a period that stabilized them and provide for a transition into ongoing community care.

Cases of potential abuse or neglect were reported immediately to the New York State Hotline. Clients were told when a call was made.

The follow-up worker also made follow-up phone calls to families where the interviewer had concerns about information revealed in the interview.

At the end of the interview, all families were asked if they had any need for service follow-up by their case manager. If a family requested services, telephone referrals and/or a case conferences took place with the case manager in order to design the best follow-up.

Instruments

Quantitative tools were used to assess the clients on depression, anxiety, family hardiness, self-esteem, and behavior. Qualitative tools were used to elicit important factors in family coping. These included but were not

limited to counseling experience, work goals, wishes and dreams, losses, school performance, and parental custody planning.

Copies of all tools are included in Appendix 3. The following is a summary of the instruments.

For Adolescents

- Life Events Inventory

Developed by the research team to measure events inner city minority youth in families with AIDS are likely to experience. Includes an index of life changes, an inventory of youth's primary concerns during the parent's illness and an index assessing youth's assumption of adult roles within the household before the parent's death. Open-ended questions focus on events youth found most difficult to adjust to, with particular attention to times of parental hospitalization, moving to new neighborhoods and schools and the formation of new families. A set of questions for youth who are living separately from their siblings was also included.

- Self-Administered, Standardized Survey Instruments

There was an introduction describing the pretested scales to be administered. The interviewer gave the youth the choice of filling out questionnaires alone or with the interviewer. A sample question for each instrument was completed together to insure full understanding and ease with the format.

State-Trait Anxiety Inventory for Children and Youth

Anxiety is one of the most common psychiatric manifestations of distress that we expected to see in the young people being interviewed. These inventory tools ask children and adolescents to describe themselves in terms of how happy, terrified, cheerful, troubled and nervous they feel at the moment the survey is being administered and in general. This instrument is widely used by researchers working with young people from a variety of social and economic backgrounds.

Rosenberg Self-Esteem Inventory

This is a short, 12-item measure of a young person's self-esteem. This measure is widely used in the field of adolescent research, including studies currently being conducted in New York City on HIV knowledge, risk behavior and prevention among adolescent runaways and HIV-positive teens. Feeling good about oneself is key to feeling capable of defining one's own limits and boundaries, especially in areas of personal decision-making related to sexual activity, school attendance, and drug use. Low self-esteem may enhance the likelihood of risk-taking behaviors in adolescents such as drug use and unsafe sexual activity.

Family Hardiness Index

This is a 20-item index to measure a family's resistance and adaptation to stress. It refers to the internal strengths and durability of the family unit in times of crisis and transition. All of the young people interviewed are experiencing the loss of a parent, one of life's most difficult transitions. This instrument provides a measure of the youth's perception of their family's ability to handle and resolve the tension and stress accompanying such loss.

Children's Depression Inventory (Kovacs)

This scale asks 27 questions designed to measure how the respondent has been feeling in the last two weeks. The young person is asked to choose among three possibilities. A sample question is:

___ I do most things ok
___ I do many things wrong
___ I do everything wrong.

The questions are somewhat simple and may be more appropriate for younger teens.

- Family Functioning Index and Educational and Community Services Use Inventory

Developed by the DAS team to focus on how the illness has affected the youth and the family and what services have been utilized and what is needed. Included are a series of questions on school attendance and performance before and after the parent's death, and use of counseling services.

- Sex and Drug Self-Report Questionnaire

This questionnaire has not been standardized and is being used in this study for the first time. It is designed to ask youth factual questions about their own sexual and

substance use histories.

For Adults

- Pre-tested Survey Instrument

Achenbach Child Behavior Checklist

This scale is widely used to document a parent's or other adult caretaker's assessment of a child's behavior and functioning. This tool provides information on the adult's greatest concerns about the child. The instrument's wide use by researchers throughout the country also provides valuable comparative information.

- Adult's Use and Need for Services

Developed by DAS team to focus on the adult's most pressing worries about the youth and what services they believe would be helpful to them personally and to the children in their care.

Data Collection

Observations

After beginning work at the Division of AIDS Services, I began keeping notes on research topics of interest. These themes often coincided with a wish list which could be presented to funding sources. A study of the needs of well adolescents in families with AIDS was on both lists and came to fruition with a grant from the National Institute of Mental Health in June, 1990. The grant application was brief and exploratory. It was not a response to a request for proposals. Nonetheless, it was awarded from discretionary funds used to support new areas of future interest.

In September, 1990, I had conversations with faculty at Hunter College School of Social Work about the feasibility of using this study as material for a doctoral dissertation. After deciding to move forward, I met with adolescent, AIDS, and family specialists throughout New York City to ask their individual advice and feedback on the exploratory study. At this time, I was keeping field notes on staff interactions, conversations with professionals, planning committee meetings and discussions with clients.

Pilot Testing The Study

After drafting and redrafting hundreds of questions to be asked of families, I decided that we would learn the most by doing. We decided to "pilot" our qualitative instruments in three families in the Bronx, far from Brooklyn where the complete study would take place. Meetings were held with case managers and supervisors in the Bronx to pave the way for this small pilot study.

Three families were interviewed and provided very important information.

- Understanding family structure and history was going to be impossible without some kind of tool to help. This was solved by purchasing the book Genograms (McGoldrick,1985) and arranging for a training session with a local hospital adolescent social worker.

- The original instrument was too long and amorphous. This was addressed by grouping questions more effectively. for both parents and adolescents.

- The families were overwhelmingly cordial, kind, generous and hospitable. Even though it was clear that their resources were extremely limited, they wanted to give the researchers refreshments and as much time as was possible.

- Clients commented on the value that the interviews had for them. This led to a burst of energy for the

research team. When the clients were supportive and encouraging about the study, the researchers forged ahead with commitment and drive.

There was much that needed changing and developing. Validated tools needed to be found and permission gained to use them. Open-ended questions needed to be combined with close-ended questions on specific life events, coping, school performance, social supports and services used. An advisory committee of experts in the field would be able to assist in a final review of the instruments and the protocol for their use.

The Advisory Committee

Selected experts were asked to sit on the study advisory committee which was scheduled to meet twice. The first meeting would review the interview process and tools. The second and last meeting would look at the results and dissemination of the study. Each of the members would also meet once individually with researchers to give individual feedback and suggestions.

The committee had members from Hunter College School of Social Work, Montefiore Medical Center Adolescent AIDS Project, Columbia University HIV Center, New York City Department of Mental Health, Retardation and Alcoholism Services and the New York City Department of Health, as well

as staff from HRA's Division of AIDS Services.

Suggestions from the Advisory Committee included:

• Use of the word "drugs" in the tool is too general. Both in order to be specific and also to create the case for Office of Substance Abuse Programs funding, specific drugs must be referred to. Since many youth do not refer to alcohol as a drug, it must be clearly referred to. Legal and illegal use of prescription drugs must be delineated as well.

• All youth need to be asked about sexual risk behaviors.

• Some questions are "friendlier" and should be moved to the beginning of the interview to create a safe and comfortable environment for the respondent. Questions like those asking about crimes and/or incarceration should be moved toward the middle or end.

• Before settling on the validated tools, review Rosenberg's 10-item self-esteem scale and other scales for measuring childhood depression, such as one developed by Beck which is more appropriate for children older than 14 years.

All of these suggestions were incorporated into the study. The Advisory Committee was extraordinarily supportive and gave the researchers an enthusiastic green light to proceed.

Focused Interviews

Following the training of staff in the Brooklyn case management office, the data gathering phase was ready to begin. The goal was to interview 20 families with an adolescent living with a parent with AIDS (called "open" cases) and 20 families with an adolescent whose parent had recently died of AIDS (called "closed" cases).

All cases with youth (age 10-19) in the family unit of the Division of AIDS Services Brooklyn office were pulled. A biographical data sheet was completed giving basic family information to the researchers. All cases that had been closed 6-12 months previously that had an adolescent in the family unit of the Division of AIDS Services Brooklyn office were also pulled.

A letter was sent to each parent or guardian requesting participation in the study. (Appendix 1) Follow-up phone calls were made to each family. Families agreeing to participate were asked to select a place and time convenient to them. The interviews were to take two to three hours. One of the three researchers went to each family. If there was more than one adolescent in the family, two researchers went to the same household. The research instruments were completed by researchers in the presence of the clients. Some parts were filled out directly by clients themselves.

Completed instruments were brought back to the office

and stored in locked file cabinets sorted by family. Interviewing began in February, 1991 and ended in October, 1991.

Open cases were easier to access than closed cases. In some closed cases, the guardian and adolescent had moved and were unknown to the public assistance system. These families could not be traced. In other closed cases, new guardians had just started to get on with a life without AIDS and did not want to look back.

Forty families were interviewed and gave most generously of their time and themselves.

Clients Not Participating

Since this study dealt with the difficult area of AIDS and was intended to focus on adolescents, we were quite concerned about family's willingness to let us into their homes. In the open cases, we were concerned that the mothers with AIDS would be too ill. In the closed cases, we wondered if the new family were prepared to discuss the past. Table 7 reflects patterns of respondent participation.

Table 7

Client Participation in the Study

Activity by Researchers or Clients	Closed Cases	Open Cases
Mailed a letter or phoned	43	34
Interviews conducted	20	20
Family said "No"	10	11
Families could not be located	13	0
Death was too recent	0	3

In the closed cases, 10 families did not wish to be interviewed. Since we wanted to know if they were all declining for similar reasons, we asked them to share the factor that helped them decide. One mother said that she didn't need help, five were not interested in reliving the death, one had a son in the hospital, and 3 had moved out of state.

In the open cases, 11 families did not want to be interviewed. Four mothers said that they had not disclosed their HIV status to others, two were too busy, one felt like a "guinea pig" being tested, three were out of town, and one was not interested.

In total, 21 families out of 77 contacted declined study participation. Given the fragile and chaotic status of many of these families, this number of refusals was

remarkably small. The reasons for non participation were 50% related to the study and 50% circumstantial. Those who refused because they could not relive the death or were concerned about disclosure were similar to half of those in the study who had similar concerns and fears.

In summary, the clients declined to participate for a variety of reasons. Approximately half declined because of the content of the study. The other half who declined to the interviewed would not have been available for any study.

Data Analysis

After the pilot study of three cases, we began the process of data analysis. I read and discussed each interview that was conducted, looking for patterns in the responses of the clients. We were also looking for areas of interest brought up by one client that might be valuable to discuss with other clients. We were also interested in the reactions of the interviewers and where these reactions might lead. For example, the researchers were greatly impressed by the strength of the clients who were living in the most adverse conditions and situations. We began to ask all clients what gave them this strength.

Upon analyzing the interviews, significant themes began to emerge. We logged these themes and also began to write case summaries which would describe specific families. This

was helpful in beginning to share our information with others.

It became clear that the best way to present the results of the massive data collection undertaken was to integrate data from all of the instruments designed specifically for this study with data from existing instruments. This included both qualitative and quantitative measures. The results are divided into descriptions of Family Characteristics (Chapter III), Adolescent Responses (Chapter IV) and Parental Responses (Chapter V).

Conclusion

This chapter described the study context--a large city agency with a model comprehensive program serving families with AIDS.

The process of the study is outlined beginning with the focus group, the grant request, the funding, and the development of the research team. The study was based on an extended planning process that brought all the players on board in an systematic and participative way. Because we went slowly and thoroughly, there were almost no obstacles. In fact, both inside and outside parties involved were pushing us to proceed because they were so interested in the results.

The decision to use qualitative and quantitative methods was a key aspect of the study. It allowed us to obtain several different kinds of information all at once.

Recruitment and treatment of subjects were particularly important in this study because the clients were vulnerable in a number of ways. They were all low income families with AIDS--a highly stigmatized condition. We were also focusing the study on adolescents aged 10-19 years who are at increased risk due to their age. There was nothing more important to the researchers than respecting the dignity and rights of the clients. There was an enormous commitment made to ensuring that the study was a positive and helpful experience to clients. The section on follow-up details the results of that promise.

Finally, the research instruments were the tools that allowed us to gather the rich and diverse information from clients. The process of choosing, refining and using these instruments was profiled.

CHAPTER THREE

FAMILY CHARACTERISTICS

Introduction

This chapter is about the families who invited us into their homes and participated in the study. It begins with a case study of Margaret who has AIDS and is worried about her adolescent daughter's serious emotional and behavioral problems. Margaret's case demonstrates the extraordinary responsibilities that she carries for others at the same time she is dealing with her own illness.

Next we look at the characteristics of the families in the study sample. Their ethnicity will be compared to the larger number of all families within the Division of AIDS Services.

It became clear after the pilot interviews that AIDS was not the only serious problem these families were addressing. For this reason, losses of all kinds are described.

CASE STUDY - MARGARET

April,1991

Household Composition

Name	Age	Relationship to Client
Margaret	(34)	client
Ida	(18)	client's oldest child
Raphael	(1 month)	Ida's son
Maria	(15)	client's daughter
Manuel	(8)	client's son
Ralph	(18)	client's nephew
George	(15)	client's nephew and Ralph's brother

Other family members

Marjorie	(41)	client's sister and proposed guardian
Carol	(36)	client's addicted sister
Johnny	(40)	client's estranged partner

Family Background

Margaret lives with her family in Brooklyn, New York and is a client of the New York City Human Resources Administration's Division of AIDS Services (DAS). Margaret was diagnosed with AIDS and became a DAS client in the summer of 1990, when she was hospitalized with a serious bout of pneumonia for almost two months. She is from Puerto Rica and still has some family there. She speaks fluent English and Spanish. Margaret does not actively participate in the Catholic church in which she was raised. She is, however, deeply spiritual in self-exploration and inner faith. She is currently taking AZT, and her health is extremely fragile. She and her physicians attribute much of her physical fragility to extreme stress associated with managing a household of seven that includes four teens--two of whom have been seriously acting out--and an infant grandson. The apartment has two bedrooms. Ralph and George sleep in the living room. Ida and her child stay in Margaret's bedroom. No one has any privacy and it is very difficult for Maria and Manuel to be in the same room. The kitchen is small and the appliances very old.

Two of the teens in the household, Ralph and George, are Margaret's nephews. They have been living with her since 1988, when they were removed from their mother's household by the Child Welfare Administration. This was due to their mother's crack addiction and resulting neglect and abuse. They have no contact with their mother.

Each of Margaret's three children has a different

father, none of whom is involved to any significant extent with the family. Margaret separated three years ago from her husband of seven years. He is a cocaine addict and is manipulative and unreliable. He currently has little ongoing contact with the children, and is not a suitable candidate for extended child care or custody. Margaret's most recent partner, Johnny, is not available to care for her or the children.

Other family members are only marginally involved; none can provide ongoing support or can be depended on to provide assistance in case of emergency. Custody arrangements have been made for Maria and Manuel, making Margaret's sister, Marjorie, their legal guardian. However, these arrangements are now in question following Maria's increased refusal to adhere to rules imposed at home and at school and her sometimes violent aggressiveness toward her peers. Margaret considers Maria her biggest problem right now and focuses most of her attention in her own counseling on her frustration and growing despair about her daughter's future and her inability to communicate with her.

Problems

The client's daughter, Maria (15), is doing poorly in school and has been suspended a number of times for fighting. She also is increasingly defiant of her mother's authority at home, sometimes staying out all night and never doing her homework. Maria is currently on probation following her arrest several weeks ago for severely beating up another girl. She is at high risk of exposure to HIV as a result of her multiple sex partners, the last of whom was in his early thirties. On being asked if she used condoms, she responded, "not usually".

The client's sister, Marjorie, refused to take Maria into her household following her arrest and may no longer wish to be her legal guardian. Margaret has been avoiding speaking with Marjorie about this, because she "doesn't have the energy to deal with it right now." There is no other reliable family member who is willing and able to take responsibility for Maria, should Marjorie be unwilling to do so.

Margaret's eldest daughter, Ida, has said that she is willing to be named Manuel's guardian, but that she will not take responsibility for Maria. Since Ida has had inquiries from Child Welfare regarding her ability to care for her own son, Raphael, the chances of her being a suitable guardian are slim.

The client's son, Manuel, is very bright and started school in an accelerated program for gifted children. Since Margaret's diagnosis and illness, his school performance has declined and his mother characterizes him as easily distracted and unable to concentrate.

Margaret feels that her disclosure of diagnosis to the children, which was done on the advice of her hospital counselor, has had many negative consequences, particularly for Manuel and Maria. At the urging of her counselor, she went home and told the children who are now in denial and unwilling to address the issue of her dying with her or anyone else. She believes Maria has not spoken to anyone, not even her two best girlfriends, about her mother's illness. An interview with Maria confirmed that she was holding this information as a secret to protect herself and her mother.

Summary

This family was selected because it typified many of the 20 open cases that we interviewed. Large households, absent fathers, extended families, adolescent unprotected sex and limited options for custody planning are features of most study families. Also, like most mothers with AIDS in this study, Margaret is a feisty, brave, young woman with needs related to her illness which are very hard to address due to the number of other people who depend upon her for their well being. Weighing heavily on her at all times, is the vulnerability of her children, grandchild and nephews when she is too sick to care for them and when she dies.

The issues of access to counseling services, family losses, denial, disclosure, and custody planning are part of Margaret's and many families' with AIDS daily lives.

Demographics

The sample was taken from family cases in the Division of AIDS Services Case Management Unit. Ethnicity, gender and age are all characteristics examined in every research study. The fourth category called "losses" is included in this study because the researchers became increasingly aware that the number of crises and losses in the families being interviewed was far beyond the norm. AIDS was not the only traumatic loss in the lives of any of these families. In some, it was not the most dramatic loss.

Ethnicity

Table 8 outlines the way AIDS has affected different ethnic groups. While anyone can get AIDS, it is not an equal opportunity disease.

Table 8

Ethnic Breakdown of AIDS in New York City

Data Group	Black	Latino	White	Other
Adult AIDS cases in NYC	35%	28%	35%	2%
Pediatric cases NYC	53%	37%	10%	<1%
Family cases DAS	33%	58%	9%	0%

The forty families interviewed were 42% African-American, 58% Latino, and 0% White. This is slightly different from the total number of families served by the Division of AIDS Services. Of the 1516 families served by the Division, 33% are African-American, 58% are Latino, and 9% are White. Families invited to participate in the study were randomly chosen from the caseload of the family case management office in Brooklyn. White families were not purposefully omitted from the study, nor were they specifically selected for inclusion when it became clear that none had been randomly selected.

As was discussed in the literature review chapter,

ethnicity does affect coping issues and styles. Throughout the interviewing, it was clear that racism had influenced the way most families were treated throughout their lives as well as since they contracted AIDS.

All families showed an enormous capacity to care fo. one another. This was especially true of sisters and mothers of the women with AIDS. In all cases, these relatives were the first ones looked to in designing a custody plan and in an overwhelmingly number of families, they were the caretakers of children during the illness and after the death.

Ethnicity and AIDS incidence is very different for men and women. Table 9 shows that in New York City, the male breakdown by race is 32% Black, 39% White and 27% Hispanic. The female breakdown by race is 52% Black, 15% White, and 33% Hispanic. This table points out that AIDS is not an equal opportunity virus. Whereas everyone is vulnerable to the virus, it is increasingly victimizing the Latino and Black population -- especially among women. This means that outreach, prevention education, and treatment need to be targeted to ethnic groups and to men and women differently within these groups.

Specifically, 85% women with AIDS In New York City are Latina and Black. In the Division of AIDS Services family unit, 92% are minority. In our study, 100% were Latino and Black. Therefore, targeted outreach and treatment are

necessary to reach and serve these women.

AIDS in New York City - December, 1991.

NYC Department of Health AIDS Surveillance Update

Cumulative Adult Cases Reported

Table 9.0 RACE BY GENDER (Percents)

	Males (n= 30,943)	Females (n=5631)
Black	32	52
White	39	15
Hispanic	27	33
Other	2	0
Total	100%	100%

Table 9.1 MALE RISK BEHAVIOR BY RACE (Percents)

	Black (n=10,004)	White (n=12,155)	Hispanic (n=8416)
Sex	37	81	47
IDU	47	12	52
Other	16	7	1
Total	100%	100%	100%

Table 9.2 FEMALE RISK BEHAVIOR BY RACE (Percents)

	Black (n=2900)	White (n=823)	Hispanic (n=1860)
Sex	20	22	32
IDU	63	59	59
Other	17	19	9
Total	100%	100%	100%

Tables 9.1 and 9.2 announce very clearly that outreach to Hispanic women regarding safer sex is of great importance. Since the overwhelming number of all women

contract AIDS through Injecting Drug Use (IDU), there must be outreach and materials targeted to women who use intravenous drugs. Knowledge of different cultures would lead us to believe that education and treatment must be done differently for and by and with all three races listed above as well as the many sub-categories within the larger race categories.

Gender

Thirty-six of the 40 heads of households in this study were women and four were men. In the 36 households headed by women there were 6 households with a male partner and 2 with a husband. In all 6 partner cases, the man was not the father of any of the children and in no cases was he named in the custody plan.

In all four households headed by men, there were wives who were very involved in the raising of the children. When couples were married, both the man and woman were involved in child rearing. However, in the 6 households with a male partner, they were neither involved with the children nor part of their future custody plan.

There were seven men with adolescents who declined to participate in the study. Of those seven, three were the primary clients and four were the newly designated guardians. Three of the men did not respond to efforts to

contact them. Of the remaining four, two believed that talking about it would upset the family, one felt that it was too soon since his wife's death and one very religious new guardian said, "if you believe in God, you do not need counseling."

It was the perception of the interviewers that it was more difficult to engage men in the study. They were more difficult to retain on the phone and generally more distrustful of outsiders. For this reason, they were contacted separately by both a man and a woman to make the outreach doubly strong. It was believed that many of the women agreed to participate because they needed someone to talk to and possibly had a service need they wanted to explore. It was observed that the men were not desirous of talking to a professional and had few service needs. Indeed, the most stable families in the study were those four with male heads of households. In two closed cases, both parents worked providing two incomes and a stable nuclear family. In the two open cases, the men were ill, but had a healthy committed woman to care for them and the children.

Women with AIDS have many complex problems. In Margaret's situation described earlier in this chapter, she was taking care of her own failing health while attending to two nephews, three children and one grandchild. During hospitalizations and extreme illness at home, she could not

focus on her own health since she had so many others to care for. This was typical of all the families we interviewed.

As one advocacy poster states, "Women Don't Get AIDS. They Just Die From It." Since the beginning of the epidemic in the early eighties, women have taken a rear seat to men in almost every aspect of diagnosis and treatment. It began in the first six months when the disease was called Gay Related Immunodeficiency Disease (GRID). All of the studies that sought the cause of AIDS were done on men. When the Center for Disease Control (CDC) began defining the opportunistic illnesses which qualified a diagnosis of full blown AIDS, they studied men and then applied their findings and criteria to women. The official diagnosis of AIDS is defined by the clinical presentation of HIV illness in men. This has yet to be corrected although vigorous advocacy in 1991 is likely to lead to some changes in 1992.

For example, vaginal yeast infection in HIV infected women is more severe and less likely to be cured by ordinary therapy (Rhoads, 1988). A woman may suffer from vaginal yeast infections even before she has thrush, a yeast infection of the mouth that affects both women and men and is officially used as one of criteria for pre AIDS. "Does it make sense that the same infection in another orifice- an orifice not present in men- is not categorized as an AIDS related condition?" (Anastos, 1989). Other serious diseases often diagnosed in women but not on the CDC list

include endocarditis, pulmonary tuberculosis, and a wide range of gynecological infections. For example, a woman may be hospitalized more than once for pelvic inflammation and a weakened immune system, but still not be defined as having AIDS. As a result of this non-AIDS diagnosis, she will be denied AIDS benefits and/or begin them far later than when they begin to be needed.

Women are usually much further along in the disease when it is diagnosed, because it is so often overlooked. In 1987 the New York Times carried an article whose headline was "AIDS Is Killing Women Faster, Researchers Say" (Kolata). The article says that there is no obvious explanation why AIDS is killing women faster and that more research is needed. In 1992, there is still no answer and there is little research exploring this question. This and many other factors result in a shorter life expectancy for women contracting the illness.

With men, the disease is most often diagnosed by internists and infectious disease specialists. Both of these specialties are at the forefront of research and treatment of the disease. In contrast, gynecologists - who would be the most likely diagnosticians for women, have been one of the last specialties to take an interest in AIDS. (Mitchell, 1988). At three major medical centers in New York, pediatricians have publicly criticized the "hands-off" approach of gynecologists toward AIDS. Dr. Janet Mitchell

says; "Even the American College of Obstetricians and Gynecologists has shown some uneasiness, not because of the gender issue but because the women presently infected are primarily women of color and, even more importantly, have intravenous drug use as a major risk factor" (1988). Obstetrician/gynecologists are sometimes more focused and interested in child birth than the disease control part of their practice. Mothers in the present study complained about physicians being scared or angry at their female AIDS patients. Since about 60% of women with AIDS have contracted it through Intravenous Drug Use (IDU), these women are not always the compliant patients medical providers prefer.

Instead, physicians often save their sympathy for middle class wives of secretly bisexual men. It gets back to the most innocent and the most guilty - adding to the oppression of the illness. All of these factors contribute to the reticence of women to trust their doctors and to the reduced likelihood that they will receive the kind of medical care they need and deserve.

In addition, there is great prejudice against women who abuse substances such as drugs and alcohol. Thelma McCormack (1986) makes a very potent case for the devaluation of women who are drunk. She points out how men in films, novels and plays almost always have a "good reason" to drink. When men become alcoholics, the popular

culture searches for the reason - one often related to the pressures of work. On the other hand, when women become alcoholics or take drugs, no cause is sought. There is an assumption that goes along with male alcoholics that they are in an active and complex struggle with choices. There is an assumption that goes along with female alcoholics that they are passive and weak and have no choices to make. These points made by McCormack are equally true for other kinds of addictions.

One additional factor makes it very difficult for women to care for themselves. One of the great strengths and weaknesses of women care givers is that the health of all others comes before their own. This is especially true for women with AIDS who are often taking care of men and children with AIDS.

Taking care of people with AIDS is a very challenging and exhausting experience. Because of the nature of the illness (its terminal and episodic nature) and because of the stigma attached to those who have the illness, there is tremendous frustration, depression, anger and oppression for the care giver as well as for the PWA. There is also gratification, reward, honesty, courage and enlightenment.

There are thousands of women in New York City involved in care-giving as mothers, sisters, grandmothers, daughters, wives and friends. As Dr. Richard Younge (1983) reports:

> "The grandmothers and the aunts are some of the real heroines of the AIDS epidemic. They give

> unquestioning love to children orphaned by AIDS, some of whom will eventually become sick themselves. As a physician trained in the best tradition of Western medicine, I believe in science and I believe in miracles, too - not just the miracles of physicians healing their patients, but of patients healing their physicians."

Many of the women in the study only addressed their own care after the care of each separate member of the family had been handled. Only when everyone else is stabilized and they fear for their own lives do these mothers seek care.

Whereas AIDS is often the major life event for the mother with AIDS, there are many other losses which impinge on their adolescent children. Half of the adolescents in the study were female.

Age

The age of adolescents in the study spread from 10 years to 19. Perhaps those 10-11 could be called pre-adolescents. It was decided that the younger children should be interviewed because we were interested in seeing to what extent they had become parentified, that is, taking charge of the household or younger children because of the mother's illness. Table 10 describes the distribution.

Table 10

Ages of Study Adolescents

Age	Number of youth	% of youth
10-11	15	25
12-13	14	24
14-15	12	20.5
16-17	12	20.5
18-19	6	10

Forty-nine percent were between 10 and 13 years old. Forty-one percent were from 14 to 17. Ten percent were 18 to 19. It was more difficult to engage the older adolescents who were often away from the home. A few were known to be living on the street or with different friends each week. Clearly, younger and older adolescents are in different phases of growth. The group from 10-12 tended to be quiet and shy about being interviewed. We usually asked them to take us to their room where they might be more comfortable. The 13-16 year age group were beginning to have a difficult time at school and at home. Many reported that they had no one except their mother to trust. At the very time that they experienced the need for the normal emancipation of adolescence, an enormous crisis came in the way. This crisis of AIDS and the potential loss of a parent

pulled them back to the family and away from emancipation. Some children wanted to stay home as much as possible to be with their mothers. Others wanted to escape the crisis and stay out all night. The ordinary experiences of testing and experimentation were severely affected by this crisis. The older adolescents were worried about their own custody and that of their younger siblings. When there was no one to take the whole family, the youngsters from 17 to 19 sometimes suggested setting up a new household in which they would be the guardian of their younger siblings. In a few cases this was tried. These adolescents had been acting like a parent for the last year or two of their mother's life and felt better about continuing in the role than about the prospect of splitting up into different foster care households.

The age span of 10 to 19 and the relative spread within these years gave the researchers a good sense of different characteristic behaviors and developmental processes experienced by the youth.

Losses

The researchers, all trained clinicians and experts in services available to people with AIDS, were deeply emotionally affected by the pilot interviews which revealed the many losses experienced by well adolescents in families

with AIDS.

It was anticipated that the teens would have many experiences and difficulties resulting from the illness and death of a primary parent. It was not anticipated that these teens would have experienced so much illness, violence, death and abandonment apparently unrelated to AIDS.

Hence, in the 40 families interviewed, each teen had an average of four major losses in the last two years. Losses were defined as death, imprisonment, drug addiction, divorce or separation of a parent and terminal illness of a family member.

These adolescents were living in a war zone of drugs, violence, prison, death and AIDS. Nonetheless, the manner in which they spoke about losses was matter-of-fact. This was described in the New York Times article on adolescents and clinics in Oakland, California (Gross, 1992). The youth revealed that "they have been raped, beaten or shot; that they are pregnant, suicidal or hungry." In our study, an absent father or a man moving through the family structure was seen by the youth as inevitable and ordinary. In one case example, a fourteen year old boy asked if he could come back again next week. I asked if he would like to be referred to a counselor who could talk with him on a regular basis. He was open to the suggestion. When I let him know that the counselor was a young man, he said he only wanted

to talk to a woman. I explored this a little further and asked him to talk about his relationship with his father and other men. He responded, "men don't talk, they just scream and hit." Few of the boy teens had a male in their lives whom they could love and trust. When asked if he ever visited his dad in prison, a youth responded, "Why should I? I never see him when he is out." Unfortunately for the teens in this study, the loss of a father was usually a permanent loss which happened a long time before they were forced to deal with the AIDS illness and death of a mother.

Loss had become such an everyday occurrence that families were coping the same way television viewers learn to listen to the violence on the eleven o'clock news - with apparent immunity. The absence of fathers is now taken for granted in the communities of color in which we interviewed families. The expectations had changed as children created a new "norm". Part of the "norm" was to avoid outbreaks of emotion which might have erupted due to fatal and tragic situations. Adolescents talked about death and loss with an eery kind of matter-of-factness. When asked about the personal impact of a loss, the response was "we just have to move on".

Nonetheless, there was one loss that was different. That was the loss of a mother. Children had learned to expect that their fathers would visit rarely and often be found in jail. They might know of their father's death, but

usually would not have direct personal day to day experience of it. But the illness of their mother did bring more emotion to the surface. All the children in the 20 open cases were living with their mother and in 18 cases her health was declining. Most had the experience of coming home to find that their mothers had been suddenly hospitalized. Many were there when the ambulance was called. Many had made those 911 calls themselves.

If children had become accustomed to homes without fathers, they certainly were not ready to be orphaned. For over half the children without custody plans, there was not only a major traumatic loss to be faced, but there was no plan for a substitute. In the five open cases where a male partner was living in the household, he was never looked to as a future guardian of the children. A clear message was delivered in these families - men are not for child rearing.

Children from these forty families not only suffered critical losses, but most had no one with whom to discuss or process it. Most of the losses in these families were wrought with stigma. Violence, prison, drug addiction, and divorce are all difficult to discuss with others. But loss of a mother,father or sibling to AIDS had much greater stigma. If most children had adapted to loss, they did not acclimate to shame and guilt. The secrecy and shame about AIDS was very great. The children's lives were filled with loss and stress at home that was never addressed at school

or with other friends. Not one child in our sample had told his/her best friend that a family member had AIDS. There was great loss but no context for bereavement or healing.

Conclusion

Margaret's family was an example of the many difficulties faced by children and a mother with AIDS. Because her daughter was "acting out" the previously arranged custody plan was in jeopardy. Her older teenage daughter had trouble looking after herself and her one month old baby. Her bright younger son was beginning to have serious problems in school. Margaret was taking care of her own health while worrying about that of her three children and two nephews, all living with her.

Women with HIV illness experience problems and conditions related to late diagnosis, misdiagnosis, inadequate treatment, under reporting, research that doesn't include women, and reduced or late government benefits.

Major issues related to ethnicity, gender, and drug use build huge barriers to care. As the mainstays of the 40 families we interviewed, these 36 women have overcome enormous obstacles to care for their families and themselves.

Finally, the teens being studied had each experienced many major losses in the last two years. Fathers were

usually absent from their lives and now they were losing or had lost their mothers.

The interviewers wanted to know how these losses had impacted on the behavior and attitudes of the adolescents.

CHAPTER FOUR

ADOLESCENT RESPONSES

Introduction

This chapter will begin with a case study of Debra who has three children. The two adolescents in this family demonstrate a range of problematic behaviors in response to the severe illness of their mother and the security of their futures.

The remainder of the chapter deals with acting out, school performance, depression, anxiety, and self-esteem. In addition, the counseling experience of the youth is examined to point out how many youth have visited counselors and how they evaluated the experience. A discussion of "best friends" opened the door to assess the impact of parental AIDS on adolescents' social relationships.

Simple descriptive statistics for data collected from the standardized instruments used for this study are presented.

Lastly, this chapter describes wishes and dreams of the adolescents in our sample. From these, the study derives insights and strategies for supporting families and adolescents in the future.

CASE STUDY - Debra

Household Composition

Name	Age	Relationship to Client
Debra	(36)	client
David	(15)	client's son
Michael	(12)	client's son
Tanya	(17)	client's daughter living with grandmother

Family Background

Debra is a 36-year-old African American female with AIDS. She became a DAS client in August 1989. Her husband James was already a client and was quite sick. James died in October of that year. Debra is very overwhelmed by the changes in her life since her husband was diagnosed HIV positive. She experiences periods of deep depression and drinks heavily. She belongs to an alcoholism counseling group but rarely attends meetings. On the surface she may appear to be coping with her difficulties, but she is barely holding on. She is unable to handle the tasks of parenting and has little control over the behavior of her children. This is particularly true of her son David's behavior.

Debra's children have expressed a great deal of anger toward their mother. They feel she did not take proper care of their father while he was ill, and blame her for his death. [Bowlby (1975) believes accusing their mother of causing the death of their father is usually a defense against accepting the death of their father. According to Bowlby, this behavior serves the function of maintaining the possibility of the dead parent's recovery. As long as someone is responsible, the possibility that it can be undone by someone remains open in the accuser's fantasy life.] The children's anger has been compounded by the fact that Debra has never spoken to them about the cause of their father's death, nor of her own illness. The children learned about their parents' AIDS diagnosis from hostile comments made by neighbors.

Problems

David, Debra's son, is 15 years old and out of control. He is the reason HRA was asked to see this family as soon as

possible. He has been described by his mother and the worker assigned to work with this family as a "nightmare" and a "terror". His acting out behavior is very self destructive. Recently, he has been staying out all night; he threatens his mother with violence if she protests. The family's case manager believes David is physically abusive to his mother, but Debra denies this. David is often truant or suspended from school. He has assaulted teachers and is disruptive in classes. Since his father's death, he has gone from being an average student in a mainstream classroom, to increasingly structured special education settings. His standardized tests show no signs of developmental delay or learning disability. His reading and math scores are at or close to grade level. The only reason for David's placement in special education is his behavior.

David had one psychiatric hospitalization two years ago, after he reported auditory hallucinations and suicidal ideation. He denies having true intentions to take his life. He also denies having any hallucinations since being hospitalized. To our knowledge, he has not been using illegal drugs, but has begun to come home drunk.

Michael, David's brother, is 12 years old and has begun to exhibit behavior problems. He has become increasingly oppositional and also threatens to hit his mother. He is often absent from school due to irritable bowel syndrome, which doctors believe may be stress related.

Possibly, Debra's 17 year old daughter, Tanya, has escaped the dynamics of her mother's household by moving in with her maternal grandmother. Tanya refused to meet with us.

All the focus on David's behavior has allowed other problematic issues in this family to exist with little attention. Debra's drinking is the best example of this. While much attention was being given to David's destructive behavior, no one noticed that Debra had stopped attending her support group and has probably returned to drinking.

Debra and her sons live in HRA-sponsored scatter-site housing. There have been complaints from other tenants to the management of the building about Debra and her children. Tenants have reported that David has vandalized the front door and that he harasses them. They have also complained about Debra's family playing loud music late at night. The building management is working with the case manager to resolve these problems. If they are not worked out, Debra may have to find new housing.

Custody planning is another area of major concern.

Debra has made informal arrangements for custody of Tanya and Michael. Under this arrangement, both Michael and Tanya will live with their maternal grandmother in her one bedroom apartment. In addition to Tanya, the grandmother has another married daughter and her family living with her. The addition of Michael to the household will make a difficult living situation even more complex.

No one in the family has been willing to accept responsibility for David in the event of Debra's death. Debra wants her children to stay together and feels that it is particularly important for David to remain with family members. One of her greatest fears is that David will be placed in foster care if she dies. Debra's mother is the most likely person to take custody of David and she expressed a willingness to do so previously. Lately, however, she has expressed more and more reservations about taking custody of David, because of his serious behavior problems and her lack of space.

Summary

This family has existed in a state of crisis since Debra's husband James became ill in 1987. Despite great effort on the family's part and dedicated work by the case manager, the situation seems to have worsened. Debra's drinking has increased, David's acting out has become more destructive, and Michael has begun to experience stomach pains. Many services have been provided, but none have significantly improved their situation. This family has been besieged by poverty, drugs, and lack of opportunity for more than a decade. They do not practice religion and do not have a spiritual bond or drive which is available to be used as an inner resource. They see themselves as a pile of problems rather than a family unit who can pull together. They also lack a community identity because they have moved so much and because their immediate needs are so great.

In addition, there is little coordination of services by the agencies involved. This family is very disorganized. Having to deal with numerous agencies at once only promotes further disorganization. In this family there is no single area of difficulty which exists independently of the others. For example, counseling services for David must include frequent interaction and consistent cooperation with supports in the school. At this point only an intense involvement in all areas of his life may undo the damage which has been done to his education. Likewise, alcohol treatment for Debra must help her find ways to cope with her parenting responsibilities and care for her own health. Services to this family must be coordinated, and the agencies providing services must recognize that problems in

this family influence each other. An isolated alcohol program here, and a math tutor there, will have a minimal effect--if any effect at all.

Unfortunately, services are not often provided in a coordinated manner. There are often a number of agencies providing service to a family, each unaware of the work of the others. This does little more than heighten the sense of frustration and disappointment for clients and workers.

Themes

Table 11 summarizes some of the data collected about the adolescents in the 40 families. Each of these measures will be described in greater detail.

Table 11

Adolescent Behaviors

Measure	% Yes	% No
Acting out	34	66
School problems	73	27
Declining school grades	58	42
Have a best friend	62	38
Disclose parent's HIV/AIDS status to a best friend	0	100
Get counseling help	43	57
Satisfied with counseling	76	24

About 1.2 million children in the United States lose a parent before the age of 15 (Weller et al., 1991). Examination of adolescents or children bereaved by AIDS is nonexistent. In a study to determine the impact of adolescent bereavement, Weller and Weller concluded that the

process of grief is more difficult for children when grief has not been anticipated, death has been linked to stigmatization, and there was not a surviving parent with economic resources to support the child through the grief process (Weller & Weller, 1991).

Acting Out

This exploratory study found that 34% of youth interviewed were having serious behavior problems--"acting out"--in school and/or at home. For the purposes of the study, "acting out" was defined as truancy, suspension from school, arrest or probation, and defiance of parental rule setting, including staying out all night or failing to inform the parent or guardian of their whereabouts for extended periods of time (i.e., days). The study adolescents were half male and half female. Behaviors were not specific to gender except for trouble with the law. The study found that 25% of male youth interviewed had been arrested or had serious problems with the police in recent months. Only 5% of the girls had been arrested. The girls acted out in school and at home in similar ways to the boys. However, the boys manifest their anger on the street and in their community through violence and thievery.

The patterns described below present a conservative picture of the lives of teenagers in New York City who have

lost a parent to AIDS. It was the research team's impression that the youth over 16 years old who had the most serious problems in coping with the death of a parent were extremely difficult or impossible to find to interview. In these cases, the custody plan that had been agreed to before the mother's death had not worked out and the youth had drifted out of contact with social service providers and stable family members. Three youth, two girls and one boy, were reported to be living with friends or other family members involved with drugs. Another 16-year-old girl was herself a drug courier between New York City and Baltimore and another boy was living on his own and was thought by case managers to be involved in some sort of devil worship cult.

None of these youth had been able to adjust to the demands placed on them in their new relationship with the guardian. In one case it was impossible for a youth who had taken on adult responsibility while her mother was ill, to assume the child-role expected of her in the new guardian's home. In two cases involving boys, the youths' problematic behaviors coupled with long-term family discord made it impossible to make custody arrangements within the family.

In Bonnard's chapter on truancy and bereavement (1961), she describes a thirteen year old boy who was truant from school and began stealing at home. Prior to the death of his parent's death, he did not show signs of maladjustment.

After death, the boy did act out due to misunderstanding and denial surrounding the mother's illness. Through six sessions of psychotherapy in which Bonnard gave the boy a realistic account of the mother's illness, he was able to integrate the knowledge and regain his previous good adjustment.

Youth in the study also "acted out" at home. A number of parents reported that they had less and less influence over their teen's behavior as the illness progressed. In part, this was due to their inability to supervise teens as they became increasingly ill. But they also often were reluctant to discipline for fear of threatening a relationship that they felt was tenuous due to an impending death. Parents and guardians of older adolescents often expressed frustration over difficulties in setting limits and in communicating with their adolescents about their behavior at home. Some parents reported that teens stayed out very late or did not come home at all on some nights. Guardians tended to be much stricter disciplinarians than the parents interviewed, though occasionally they expressed concern about being too hard on youth who had recently suffered the loss of a parent. Youth who were acting out at home were often having difficulty at school.

School Performance

Not surprisingly, 73% of all youth interviewed reported having problems in school related to grades and to behavior. Almost 60% of youth had experienced a change in their grades associated with the parent's illness. In almost all cases, grades went down. Among the 40% who reported no change in their grades, the majority noted that their grades had always been poor.

Winnicott (1965) describes a bereaved eleven-year-old by whose father drowned while sailing with him on the boy's birthday. Eight months after the tragedy, the boy was referred to therapy due to somatic complaints and withdrawal from school work. In therapy, the young boy allowed himself to recall the events and relive the drowning incident. This helped him to understand some of his difficulties with feelings and with his parental relationships. This kind of therapy would be helpful to many of the study children who have blocked out the illness and death from their own experience and never had the opportunity to share it with anyone else.

A number of therapeutic studies in which children are helped to recover memories, feelings and misconceptions about illness and death point to children's progress in moving ahead constructively. (Kliman et al., 1969; Barnes, 1964).

There was an identified pattern that youth whose grades had gone down often regained past performance levels after the parent died and the living situation was stabilized. This was particularly true for younger girls, perhaps because they were less likely to have established behaviors that compromised school performance or the stability of their living situations.

Many ill parents told us that their greatest concerns were focused on their son's or daughter's poor performance in school and its long-term negative consequences for future employment and security. The knowledge that they would not be available to provide future stability and guidance to their children led many parents to place great emphasis on the importance of regular school attendance and good grades. School attendance and grades were also a major concern of guardians, many of whom had agreed to take the youth into their home only if the youth went to school regularly and performed well. Youth who had lost a parent often told us that it was important for them to do well in school because it had been their mother's greatest desire that they graduate.

Parental illness and death had usually placed serious strains on many youth's already ambivalent relationship with the school system. At best, a youth did not change schools during the illness or after the death and had an understanding teacher and principal aware of the loss and

transitions taking place in the home. In a very few cases, younger youth reported that they had formed strong relationships with counselors at school. These counselors usually made home visits and were available to provide ongoing support and to advocate on the student's behalf when problems arose at school.

At worst, a youth had no advocate and found the school totally lacking in support. Not able to concentrate in the classroom, the student began to fail and eventually left school altogether. In a number of cases, generally involving older adolescents, fighting, disruptive behavior and insubordination resulted in suspension from school. Other adolescents simply dropped out. For girls, pregnancy was often the reason given for dropping out.

Some youth miss considerable amounts of school during the parent's illness because they are assisting the parent at home or accompanying the parent to a clinic. Youth also reported not wanting to go to school because they feared returning home to find that their mother had been hospitalized, or even worse, had died. It was not unusual for parents to be hospitalized multiple times during the course of their illness and many youth described instances when emergency medical services had been called to the house, often when they were at school. Most frightening was the possibility that they would arrive home, find their mother gone, with no indication of where she was

hospitalized or if she had died. When a child did find out the hospital where his/her mother was staying, they were often not allowed to visit because of hospital rules regarding children's visitation. This magnified the fears and anxiety of the children.

Disruptive behavior and poor grades often resulted in a student's placement in special education. Once in the special education system, it is difficult for a student to be mainstreamed again into the regular school curriculum. Youth who have problems controlling their behavior may find themselves in more and more restrictive special education settings for behavioral reasons alone. Academically unchallenged, these youth, their parents and their guardians experience great frustration at what they feel are obstacles to their ability to access the best available educational opportunities.

Two of the young people who had dropped out had gone on to complete GEDs, others wanted to take GED courses or expressed a desire to return to school and complete their high school degree. Only 1 of the older adolescents (over 16 years old) interviewed mentioned a counselor or school staff person who was aware of their loss and had been available to advocate for services and provide support. In this case the staff member was the boy's football coach, whose loss of his own mother as a teen fostered the growth of an unusually strong connection between the coach and the

DAS client's son.

Getting Help: Counseling Experience

Youth were asked to describe what counseling experience they had in the last two years, including where they had received the counseling and whether they had found it helpful. Of the 59 youth interviewed, 43% had counseling or were currently receiving counseling; 57% had received no counseling services in the last two years.

Over 50% of the youth interviewed who had received counseling did so at a community clinic or through the school system. Three of the 25 youth who had counseling had seen a counselor at a private clinic. Five had seen a counselor at a hospital outpatient clinic. One youth had been hospitalized and three had received services from other providers, including HRA staff. Of these youth who had received counseling, 75% told interviewers that they were very satisfied or fairly satisfied with the services. Youth dissatisfied with counseling felt they had been somehow coerced into seeing a counselor. One youth had seen a psychiatrist briefly during hospitalization following a suicide attempt; a youth in special education had seen a school counselor who he felt was very punitive.

Although there was no formal assessment of the counseling services received by the youth interviewed, it

was the research team's impression that quality varied greatly. Most youth receiving services through the school system were counseled by guidance personnel, normally as a result of problems related to attendance and\or discipline. In general, youth receiving counseling in school were not being seen by staff with expertise in psychological counseling. The exceptions were several children attending schools with specialized counseling services, including groups for children who had recently lost family members.

Four youth requested counseling services in the course of the interview and counselors thought that a number of others would be helped by counseling. In cases where youth requested counseling, they often asked that the interviewer be the counselor and that counseling occur in the home. Two youth had been offered some type of counseling services at school, but had refused them because they felt that their confidentiality would not be maintained. In other cases, youth had requested counseling but had either not been referred or had been referred to counselors whose offices were difficult to reach.

The research team provided follow-up, primarily in the form of referral to community services, in families where an acute need was identified during the course of the interview. Referrals to counseling services were difficult to complete for a number of reasons, including lack of services, inaccessibility of services (particularly for

younger youth not permitted to travel alone on public transportation), absence of an adult family member to escort youth to services, and long waiting lists for service at community mental health centers. Lack of transportation options acceptable to families was a major obstacle to accessing mental health services for young family members. This was particularly true for families who requested services outside their neighborhood in order to maintain confidentiality.

Additional counseling issues that came up in the course of the study included ethnic and generational differences in comfort level with accessing counseling services. Five youth stated that they were uncomfortable talking to someone they didn't know and who was so different from them. Difference was defined by the youth as counselors who were much older and/or Caucasian. When the youth did access counseling it was short-term--often for one or two sessions. It was complicated for family members to keep appointments and the disorganization in their lives prevented them from developing trusting relationships with counselors. Even when the family sustained the relationship, they frequently reported interruptions in counseling, sometimes for many months at a time, due to their counselor at the community mental health leaving the job and their case awaiting reassignment. Progressive severity of illness, hospitalization, lack of transportation and moving were

additional barriers to continuity of counseling in these families.

The research team found that guardians were in general reluctant to consider counseling as a service from which they themselves might benefit. Often they referred to themselves as the family member who was the "strong one", able to take care of every one else and therefore not in need of formal support. Grandmothers who were guardians spoke frequently about their reliance on their church and their church-based network of friends. Even in cases when the guardian had not been able to disclose to other church members or the priest or pastor that there was HIV in the family, they found tremendous support from the church.

Studies in childhood bereavement which were done by Erna Furman (1974) involved 23 cases of children who had been orphaned through the death of a parent and who had received five-times-weekly psychoanalysis via-the surviving parent. Many of the case examples reflect feelings similar to those of the study children. Furman's only general statement that "anyone concerned with bereavement needs to appreciate the limits of his helpfulness and the unique impact of each death" is totally applicable. Contrary to some parent's fear of exposing their very young children to death is Furman's belief that normally developed children from two years old can understand death if it had been previously discussed around common encounters. It was much

harder for a child to understand when they first learned about death in conjunction with the loss of a loved one.

Social Relationships

Assessment of youth's social relationships indicated that 38% did not have a best friend. Four youth told us that they did not have any one they considered a friend. They referred to classmates and neighbors as "associates", explaining that there was not the trust needed to qualify the relationship as a true friendship. Most of the youth interviewed live in neighborhoods plagued by drug selling and use. The danger on the streets and the absences of safe public places to congregate and to play makes it difficult for these youth to form friendships outside the home environment. Instead, their best friend is likely to be a sister, or a cousin or the child of a close family friend who is already in the home frequently.

Moving and changing schools increases the social isolation of youth in families with AIDS. While some youth who had moved still maintained some connection to old neighborhoods, most had lost contact with their former neighborhood and school friends. In cases where the guardian, usually a grandmother, had moved into the household to care for the dying parent and then decided to remain with the children, in the parent's apartment an

important source of stability in the lives of the youth was maintained. For those youth who had moved and changed schools, an important source of stability in their lives had been lost. Telephone contact was sometimes maintained by older teens with friends left behind in previous neighborhoods, but this was the exception rather than the rule.

Sex and Drug Behavior

Parents also expressed concern that their older adolescent children were themselves at high risk of HIV infection. Three had attempted to speak with their teen age children about risk and how to protect themselves against exposure. They felt that their warnings had been ignored. One mother informed interviewers that her experience in trying to educate her 16-and 18-year-old daughters about HIV had led her to believe that youth would be much more likely to listen to and act on information about their risk of HIV infection and how to prctect themselves if the message came from another youth.

Sixteen of the older adolescents interviewed filled out a self-report questionnaire on their sexual activity and their own drug use and that of their family and friends. Of the 16 youth who reported, nine had sexual intercourse at least once. Four out of the five girls had been pregnant at

least once and one out of the four boys had fathered a child. In terms of drug use, three youth reported that they used marijuana, one youth reported crack use by family members and two youth reported use of other illicit drugs by family or friends.

Depression and Anxiety

There was conflict between the data collected through quantitative pre-tested survey instruments and that observed qualitatively by the researchers. Whereas the instruments did not demonstrate that these youth scored in normal ranges of depression and anxiety, researchers observed signs of clinical depression in half the youth studied. All test score data was analyzed by gender, ethnicity, and open or closed status of the case, but no significant differences were found in any of these categories.

Evidence of the emotional or mental health distress of the youth was assessed by administering the Children's Depression Inventory (Kovacs, 1983), the Spielberger State Trait Anxiety Scale (Speilberger, 1983) and the parent version of the Child Behavior Checklist (Achenbach, 1978). The mean scores of the Children's Depression Inventory were within the normal range (M=11.1 for open cases and 8.4 for closed cases where the parent had died). Because of the small sample size of 20 open and 20 closed cases, there were

no significant differences between the open and closed cases, gender or among ethnic groups. The open cases had higher scores on the depression inventory, which reflected the stress of living in a family in which a parent is living with AIDS. The mean scores for our study were not significantly different from other samples of youth with juvenile diabetes (M=5.9), child psychiatry outpatients (M=9.7) and youths in Toronto public schools (M=9.3). They were, however, the highest.

The scores on the state-trait anxiety scale were also in the normal range and were not significantly different between the open and closed cases, gender or among ethnic groups.

On the Achenbach Child Behavior checklist, externalizing symptoms were common (62%). However, only 10% of the youth scored above the cutoff score for clinical severity on more than one scale; 25% met the clinical cutoff on one scale. These data indicate that adolescents in our sample of families with AIDS are distressed, but psychopathology does not characterize the majority of these youth.

Studies examining bereavement in the surviving partners of gay men indicate that both care-giving to an AIDS partner and the death of that partner are accompanied by depression (Folkman, 1991) and exacerbated by the stigmatization of the disease (Chagoya & Citron, 1991; Glassman, 1991). However,

there are few data on adolescents' reaction to loss and death, (Gersten, Beals, & Kallgren, 1991).

Evaluating the degree of emotional distress experienced by the adolescents we interviewed was, at times, difficult and frustrating. Part of the difficulty came from being unable to reconcile the quantitative data with our own impressions based on home visits and direct contact. The assessment tools may have missed a crucial element in the lives of our families and, more specifically, in the lives of the adolescents in these families.

During the interviews we witnessed a great deal of pain and fear. We also witnessed great efforts to put things back together, control the sadness, and go on with life. Our standardized measures seem unable to describe the complex means by which these families have come to deal with loss, and protect themselves from sinking to the depth of their pain. We were witness to their fights against an adversary that has yet to lose, and their struggle to care for each other. The families we visited were experiencing a level of pain and dread most of us cannot begin to imagine. Perhaps this is why, at first glance, we were able to welcome the idea that our adolescents are not measurably distressed despite living in the midst of a life altering trauma. We were initially comforted by the suggestion that our adolescents are not deeply distressed, nor very different from other people their age experiencing lesser

trauma.

This was particularly appealing since so many of our youths are struggling with their sense of self, and fear of being rejected by friends if anyone learns the family secret.

Thomas J. Cottle's work on children's secrets (1980) pre-dates AIDS, but corroborates the findings in this study. Cottle uses "life study" as his research tool. That is, he lets people describe in their own words how their lives are being led. He states:

> "When children keep the sort of secret we have been examining in these pages, they come to believe in the mythic nature of their own existence only partly because they know a lie must be preserved. The lie, literally the inability to tell someone the truth, not only affects the perception of the world as being corrupt or counterfeit but colors children's own sense of themselves. So secretly, children view themselves as corrupt or counterfeit."

In our study of youth in families with AIDS, the children were either being lied to by a parent about HIV, or when they knew about HIV, were told to keep it a secret.

The view of our youths as within the "normal range" of emotional distress does not always endure. For we continue to see youths in trouble with the police and having problems in school. Parents and case managers continue calling for help with adolescents whose behavior is out of control. Once in the home, the professional must take the time to

slowly develop trusting relationships with youth who have learned that it is not good to trust anyone. Five of the youth who reported that they did not have a best friend said they only had "associates" - a term used in the drug dealing culture.

Some families, particularly after the parent has died, seem to be invested in having things appear stable. Generally this manifests as a blanket suppression of emotions. In one family, two interviewers entered an apartment with two televisions on in the living room and seven people watching. The parent answered the door and returned to watching television. No one acknowledged the presence of the interviewers. Television was the vehicle used by the family to relate. The interviewers spoke to three children briefly and left without conducting formal interviews. In this family, coping was done by watching other people's lives. Dealing with the situation at home was far too difficult. In this family the mother was very sick and had no plans for the future. Her five children were without custody plans and resources.

In fourteen of the closed cases, the emphasis was on continuing life, getting over the loss and "being strong". There was often a feeling, when visiting these families, that the visible order was brittle; it was liable to crack and give way to a very powerful sadness. These families believed that an open expression of their pain, their loss,

or their anger, could destroy their lives. Their depression remained veiled in denial, and rigidly kept at a safe distance. Only two adolescents would identify themselves as depressed or anxious. However, 58% of the adolescents we interviewed were judged by the interviewers to be clinically depressed. Some had an agitated depression or experienced some combination of depression and strong anxiety. Others were withdrawn, their affect was blunted, and they showed little interest in their surroundings.

It was more difficult to recognize those who experienced a combination of anxiety and depression because they engaged in a great deal of acting out, and much of their acting out was counterphobic. Bravado takes the place of tremendous fear. Krupp (1966) is discussing this same issue when he states that many adolescents who become involved in crime are often defending against feelings of hopelessness, anxiety and depression. Adolescents are often unable to formulate direct statements to describe their emotional experience. This is particularly true of adolescents who have experienced abuse and have learned from experience to be guarded and hide their vulnerabilities at all times. Many of the adolescents in our sample have experienced some degree of mistreatment or neglect, and have developed an exceptional ability to act out their most disturbing or frightening emotions. Their behavior seems designed to confuse and distract adults--to keep parents,

teachers and case managers preoccupied with the behavior and too overwhelmed to notice the emotional issues involved. Some adolescents we interviewed had a repertoire of maneuvers to shield them from the depression and fears that are just below the surface. It is this hidden vulnerability which did not appear in the pretested instruments, but was felt by the interviewers.

For example, David stays out all night, is regularly truant or suspended from school and has begun to use drugs. His mother--who has AIDS--is unable to control his behavior and describes her 15-year-old as a "monster". When seen by the study clinician he was characterized as a skinny, anxious 15-year-old boy who was obsessed with video games and dreams of being a video game designer when he grows up. He is no monster, and the nightmare experienced by his mother and caseworker is only a piece of the nightmare he has been living with for the last two years.

David's father died of AIDS in 1989. The effect of this loss on David is not directly addressed in the case record. In fact, we have no indication that his grief was recognized by anyone in any way. However, a careful look at the contact notes in the record told us two things: first, that David's behavior has meaning. He is trying to communicate an experience he cannot make sense of. The second thing the case record told us is that David had made other, less self destructive, attempts to communicate his

feelings which did not get anyone's attention. For example, when his father was sick, David helped his mother care for him because he was aware she was feeling overwhelmed and stressed. David would not go to school then. He told the case worker he didn't want to go to school because he was depressed, tired and afraid something would happen to his father or his mother. He also talked about having recurrent nightmares in which his father turns into a monster and eats him. The case manager commented, "Whenever I am there, he tries to take all my time." It is painfully clear David was asking for a response. He didn't get anyone to respond until he began acting out. It is not the response he hoped for, but it draws some attention to him and his problems.

Another example is the case of Maria, a 15-year-old female whose mother has had AIDS since 1990. Maria's mother considers Maria her biggest problem right now. She reports frustration and a growing sense of despair about her daughter's behavior and her future. Maria has a number of problems, all quite serious. She has been left back once and continues to do poorly in school. She is truant and has been suspended a number of times for fighting. She is also increasingly defiant of her mother's authority at home, sometimes staying out all night. Maria is currently on probation following her arrest several weeks ago for severely beating up another girl at school. She is at high risk of exposure to HIV as a result of her multiple sex

partners, the last of whom was in his early thirties.

During most of the interview she was rude, uncooperative and insulting to the interviewer. Her responses were short and exhibited disinterest toward the entire process. The interviewer found himself becoming increasingly annoyed, distracted and confused. He was considering stopping the interview, but decided to ask one final question. The question was: "What do you want to be when you grow up?" She responded; "I don't want to grow up." Her voice showed emotion for the first time, and she struggled to keep her tears to herself. Everything seemed to change at this point, the room felt different, the annoyance the interviewer was feeling was replaced by an awareness of how scared and lonely this little girl was. After a while she continued: "I wanted to be a nurse because my mother wanted me to. I was even going to apply to a special high school for health care. I don't care about school anymore . . I don't care about anything." Suddenly her behavior did not seem so incomprehensible.

The interviewers were sometimes surprised by the positive attitudes of the youth in the study. Scores on the Family Hardiness Index indicated that 87% of the youth responded to the statement "we do not feel we can survive if another problem hits us" as false or mostly false. Also reflecting their optimism, 88% youth answered true or mostly true to " many times I feel I can trust that even in

difficult times that things will work out." On the Children's Depression Inventory, 100% of the youth answered, "I am sure that somebody loves me." 95% answered that they liked themselves, 5% said that they did not, and 0% said that they hated themselves. 84% reported sleeping pretty well.

There are, therefore, no simple conclusions to draw about depression and anxiety in these youth. Scores on pre-tested instruments reflected some definite signs of strength and optimism. Behavior difficulties and underlying emotions which sometimes came to the surface in the interviews showed that some of the youth were not disclosing their sadness and difficulty to themselves or to others.

Descriptive Data From Standardized Instruments

The data collected from three standardized instruments were analyzed by gender, race and case status (open or closed). Although some differences did appear for specific subscales, there were no statistically significant differences between groups. As mentioned earlier, no normative data are available with which to compare the study population. For McCubbin's Family Hardiness Index minor comparative data are available and presented.

As shown in Table 12, the mean and median scores for the study population are similar to those of the population

of 304 non-clinical families in Madison, Wisconsin.

Table 12

Comparing McCubbin and Study Data on Family Hardiness

Study	Mean	Median	SD	Range
McCubbin n=304	47.4	48.0	6.7	0-60
Draimin n=61	43.6	43.6	8.8	0-41

Tables 13,14, and 15 show comparisons of scores by gender, race, and case status, respectively. There were no statistically significant differences observed.

Table 13

Mean Scores by Gender

Measures	Boys	Girls
Family Hardiness Index		
Commitment	19.6	17.6
Confidence	8.1	8.9
Challenge	10.1	10.9
Control	6.5	6.0
Total	44.2	43.3
Children's Depression Inventory	9.1	10.6
Rosenberg/Hyler Self Esteem	30.4	31.6
R/H Self Esteem Lie Scale	9.6	9.5

Table 14

Mean Scores by Race

Measures	Black	Hispanic
Family Hardiness Index		
Commitment	18.5	19.9
Confidence	8.9	7.6
Challenge	11.9	9.6
Control	6.5	5.5
Total	45.8	41.4
Children's Depression I.	9.0	9.0
Rosenberg/Hyler Self Esteem	30.8	31.1
R/H Self Esteem Lie Scale	9.4	9.5

Table 15

Mean Scores By Case Status

Measures	Open	Closed
Family Hardiness Index		
Commitment	18.7	17.0
Confidence	8.9	8.4
Challenge	10.9	10.4
Control	6.1	6.1
Total	44.6	41.8
Children's Depression Inventory	11.1	8.6
Rosenberg/Hyler Self Esteem	31.5	30.7
R/H Self Esteem Lie	9.2	9.8

Wishes and Dreams

Youths' wishes and dreams indicate the salience of the parents' illness and the concern about the stability of the family's living situation. The following are the direct quotes of selected youth who were asked to state three wishes and dreams:

Youth who have lost their mother said:

> To have my mother back, have fun and be grown up.
>
> To have my mother alive, to have a mother and father, and to live in a world where there were no drugs, lying or stealing.
>
> To not be left back in school, to go to camp and to have a lots of money.
>
> To be rich, for everyone to be immortal and to have an infinite number of wishes.

Youth who are living with their mother with AIDS said:

> To cure my Mom, to do well in school, and for the world to be good.
>
> To have 100 more wishes, for my Mom and family to be in perfect health, and for friends and family to all live across the street.
>
> For my Dad to be alive for my Mom to feel better and for us to live in a bigger house.
>
> To have a drug-free country, to live where no one would ever die and to live with my Aunt Susan.

These wishes reflect the hope and sadness of the youth who had lost or were losing their mothers.

Conclusion

Debra's family and the others referred to in this study point out that adolescents in families with AIDS utilize many of the coping strategies used by other troubled adolescents. Some of these behaviors result in an exit from school and an entrance into the criminal justice system. Some behaviors are a way of expressing the enormous tide of frightening feelings that are stimulated and created by the loss of a mother with AIDS.

The adolescent is a part of the whole family dealing with the problem of AIDS. Each family has learned to cope with a major assault on its wholeness. Adolescents, as a group, often fall away from their families at a time when they most need the structure to deal with their own growth and development. Adolescents need to be assisted to express themselves in healthy ways. The adolescents in this study were often dealing with complicated and complex issues without the assistance they needed. In response, the adolescents expressed their wishes and dreams in terms of a world with parents, personal safety and no drugs.

CHAPTER FIVE

PARENTAL RESPONSES

Introduction

Every family has its own way of dealing with a major life event. As was described in chapter three, families with AIDS have experienced an average of four traumatic life events in the last two years. Families dealing with AIDS must absorb the problems of any large loss, but also must deal with the huge stigma that society has imposed upon families with this disease.

The following case study of Annie describes how one family is attempting to cope with this stigma. This family's coping strategies illustrate how the use of denial and secrecy impacts negatively on the management of the family.

More generally, this chapter examines the issues of disclosure and custody planning--two of the most difficult tasks that a family with AIDS must address. It also looks at Rosa and her family's positive coping strategies and where they find power and strength in their struggle.

Case Study - Annie

Deceased Parent

Annie (Died 12/90) DAS Client)

Household Composition

Name	Age	Relationship to Client
Rosie (71)		client's mother
Martin (17)		client's son
Katy (9)		client's daughter
Maddy (5)		client's daughter (HIV+ DAS client)

Other Family Members

Marie (30)	Rosie's daughter; client's sister
Simone (20)	client's daughter
Francine (22)	client's eldest daughter

Background

Annie died December 4, 1990. Three of her children, Martin, Katy and Maddy, live with their maternal grandmother, Rosie. Maddy is HIV+ and symptomatic. Her health right now is fairly good and she is going to school regularly. However, a home attendant is present to assist with her care when she returns from school and she receives visiting nurse services every three weeks.

Rosie and her family are from Haiti and they maintain close ties with family and friends there. Rosie is 71 years old and speaks and understands very little English. Before Annie became ill, she lived with her second daughter, Marie, in Queens. Also living with them was another child of Annie's, a daughter named Simone. When Rosie moved to Brooklyn to care for Annie and her three youngest children, Simone remained in Queens, with Marie. Annie's oldest daughter, Francine, is recently married and in the Navy in North Carolina. Annie's children are close and see each other and speak on the phone fairly often.

Annie's sister, Marie, is very involved with the family and is very close with Rosie. Marie is 30 years old and is a nurse. She assists Rosie in negotiating the social service system, relieves her of child care responsibilities when possible and is generally available for companionship and support.

The interview with the family was not conducted in

the usual manner. Issues around disclosure, the recentness of the death and fragility of the family, and the language barrier with Rosie made a formal interview impossible. Instead, the interviewer spoke first with Rosie and Marie together, then with Katy and Martin together, and finally with Martin alone. The case manager, who speaks Creole, was present throughout.

Problems

Rosie and Marie need assistance in deciding whether to talk with Katy and Martin about the cause of their mother's death and the fact that Maddy is HIV+. To date there has been no open acknowledgement that Annie had AIDS or that Maddy is sick and receiving visiting nurse services. Rosie and Marie believe that Martin knows that his mother had AIDS even though no one has told him directly. They are uncertain if Katy knows.

The entire family is in the early stages of grieving for Annie and might benefit from seeing a bereavement counselor. Rosie reported having trouble sleeping and should perhaps be evaluated for depression. Four months after the death, Rosie says she still sees Annie wasted away in her bed, and the sickroom is unused and still contains medical equipment from Annie's last months at home. They all are having a very hard time coping with their feelings, and are reluctant to talk about how they are doing. Resolving their grief is made much more difficult by the secrecy around the cause of death. Rosie relies heavily on her faith in God to provide her with strength and she sometimes talks to Marie about how she feels.

Martin told no one that his mother had died. His football coach, whom he is very close to, only found out about the death through talking with Marie about Martin's declining school performance several months after Annie died.

Rosie believes that moving out of the apartment where Annie was so sick will make it easier to go on living. They are looking for a place to live in Queens so that they can be nearer Marie and other important family resources. Martin will continue going to high school in Brooklyn. Katy and Annie will transfer to schools in Queens.

Martin has not been doing as well as he usually does in school and lately has been getting involved in fights. He's in danger of failing chemistry, but recently started getting tutoring, which he feels will help. He's very motivated to go on to college, either to be an architect or a graphic artist. He would be interested in getting some on-the-job experience in a designer or architect's office this fall. Right now, his main goal is to get a "real" job for the summer.

Katy would be interested in an after-school activity,

particularly dance classes, if they were within reasonable travel distance of her home.

Marie would like to be able to relieve her mother of more of her child care responsibilities. What she would really like to do is take the children for a month this summer and send Rosie to Haiti for a vacation.

Summary

This is a family with many strengths, going through a very difficult period. The children are smart, motivated in school and well-behaved, and they have the support and commitment of their aunt and grandmother. Enhancing the children's strengths, bolstering Marie's and Rosie's ability to cope with their own grief and helping them address Maddy's illness and the issue of disclosure to the children will be of great benefit to this family.

Rosie and the children are reluctant to share their feelings and are unlikely to access counseling unless there is strong support to do so from Marie. Marie is receptive to the idea of counseling for Rosie and herself as a way to discuss how they may want to talk about Maddy's illness and possible death with Martin and Katy and with Maddy herself. The counselor must be Creole speaking, which may be something of an obstacle.

This family was typical of the Haitian families interviewed in that AIDS had not been discussed openly. Even after Annie had died and there was another sick child in the home, the illness had not been acknowledged. Rosie was the leader of the family and as the grandmother, had many problems to address. The most frequent custody plans name the mother or sister of the person with AIDS to head up the new household. In this case, Rosie had both language and cultural differences with her grandchildren. This was common in Latino families as well.

Stigma

There can be no discussion of how parents respond to AIDS without first addressing the stigma that still surrounds HIV infection and AIDS. Twelve years into the epidemic, in the communities most ravaged by disease, families continue to hide the presence of AIDS, children are ostracized in school and family members continue to shun

those infected for fear of transmission through casual contact. Families that disclose the presence of AIDS do so at great risk.

Stigma is a product of fear and ignorance and the ability to create separations between oneself and others, creating a division in the mind where none exists in reality. The stigma that surrounds having a parent with AIDS affects thousands of children and youth in New York City and many more around the country. And it affects them regardless of whether or not they are aware of their parent's HIV status and if they are aware, of whether they have shared that information with others. A child who knows must incorporate the question of "who should I tell" into routine decision making. A child who does not know, in many cases lives with the knowledge that there is a secret, something hidden that can not be spoken of.

The stigma around AIDS and its effects on families, particularly on children and youth, is an issue to which all professionals and others in contact with young people must be sensitized. Individuals cannot address stigma until they are sensitive to the fact that it exists and that it affects many of the children and youth they serve. Teachers who recognize the effect of AIDS on their students and the community can play a powerful role in changing the attitudes of their students and fellow teachers. A school that brings in bereavement counselors to work with students on an

individual and group basis raises the awareness of the entire school system that a problem exists and that it can be addressed in very practical and healthy ways.

The grieving process is further complicated by the fact that the family must come to grips with not only the dying of a family member, but also with the life-style associated with the disease--whether it be homosexuality, drug use, perinatal transmission or unsafe sexual behavior. (Burnell & Burnell, 1989). In discussing anticipatory grief in AIDS patients, Burnell and Burnell focus on the loss of a parent or lover to an adult homosexual. There is no mention of children's grief for the loss of a parent.

For some of our families, stigma brought alienation, threats, poor medical care, insulting attitudes and assumptions made about lifestyle choices, and a host of other large and small indignities. In some cases, the actions were deliberate, but often the act was unconscious.

Denial

Sometimes the parent's reluctance to discuss custody arrangements lies in the fact that there is no suitable family member or friend who can or wants to take custody. Or, there may be several family members who want custody and the parent may be unwilling to jeopardize her relationship with one by designating the other as the guardian. More

commonly, however, the major impediment to formalizing custody arrangements appears to be the parent's decision not to disclose her HIV status to other family members, including those most suitable to act as guardian, and their denial of the seriousness and terminal nature of the illness. Reluctance to execute legal documents is also influenced by previous unpleasant experiences with lawyers and the court system, by misunderstandings about the rights of the guardian before the death of the parent and by magical cultural beliefs that in acknowledging the possibility of an adverse event, as in preparing a will, one greatly increases the likelihood that it will happen.

In the course of the study, we became more and more aware of how difficult it was for parents to develop workable custody plans and to then formalize those plans through the execution of a will and/or guardianship deed. Although the court is not obliged to follow the guardianship wishes of the parent as documented in the will, judges do give significant weight to the parent's choice. There are a number of programs that have been established to ensure DAS clients access to legal services. Thus, we conclude that the failure to address custody planning in a timely fashion and to formalize custody arrangements is not the result of lack of access to legal services.

The experience of the research team and that of case managers has been that parents wait until they are quite ill

to make custody arrangements and prepare wills. In fact, it is not unusual for a parent to decide to prepare a will when she is in the hospital, and in many cases the process can not completed before the parent dies. In families where relatives are competing for placement of youth in their homes, youth may remain in limbo for up to a year as family members turn to family court to resolve the question of "the best interests of the child."

Parental Themes

Table 16 provides the two most important findings in the study. First, almost 40% of the youth did not know about their parent's type of illness and second, over 50% did not have a viable future custody plan.

Table 16

HIV Disclosure and Future Plans For Youth

Measure	% Yes	%No
Disclosure to youth	61	39
Viable Custody Plan for Youth	48	52

Disclosure

In order to protect a parent's decision on disclosure, all interviews were conducted to allow the youth to reveal what they knew about the parent's illness. AIDS was not discussed unless the youth indicated awareness that their parent had AIDS. Youth were all asked if they knew the illness of their parent and what they thought it might be. This exploratory study found that 40% of the 59 youth interviewed did not know that their parent was living with AIDS or had died of AIDS.

Decisions about who to tell about the HIV diagnosis and when to tell them, are issues of major importance in all families with AIDS. Very few families had chosen to reveal their HIV status outside the family. This, however, did not necessarily mean that neighbors and others in the community were unaware that a family member might have HIV. The suspicion that a family might be affected by HIV often resulted in taunting, threats of violence, and not uncommonly, a need to rehouse a family in a neighborhood where their anonymity could be better protected. While we occasionally heard about health care workers, neighbors and school personnel who had been wonderfully responsive to families following the parent's deliberate disclosure of HIV, these stories were rare. In most cases, parents recognized the need to protect their own privacy and that of their children to disclosure outside the family. These

parents had assessed the stigmatic consequences and decided that the risks were too great.

Some families were extremely eloquent about the effect that stigma associated with AIDS had on their lives and on their access to informal and formal social support networks:

> "I go to my church every week and even help cook food for people with AIDS, but I would never tell anyone that my daughter has AIDS. I couldn't bear to have a bad experience that would prevent me from having the church. It's the most important support in my life."
>
> "I have seen what happens when people on the block know about someone having AIDS. No one wants to play with their kids and it doesn't change--even when the parent dies."
>
> "I don't want anyone to know. It would just give me more problems than I already have."

One mother's recounting of an incident involving her 10-year-old son struck interviewers as being particularly poignant and very illustrative of the poisonous effect of stigma on communication. Her son's teacher had brought up the subject of AIDS and a fellow classmate had revealed that she knew a great deal about HIV. When asked how she knew so much about AIDS, the girl disclosed to the class that her mother had AIDS and was very ill. The response of the class was immediate and extreme: mayhem ensued and many children left the room or moved as far as possible from the girl. Our client's son did the same and felt terrible about having done so. As he told his mother, he feared that staying in the room or behaving differently from his classmates would have been interpreted as an admission that he too had AIDS

in his family, a step he clearly was not prepared to take. But her son was left with the guilt and shame of secrecy and the abandonment of his classmate with whom he had so much in common.

Some of the parents interviewed and many of those who had died had chosen not to inform all or some of their children of their HIV status. Many parents told us that their decision not to inform was based on a desire to protect the child. Often they felt that a child, even an adolescent, was too young or immature to understand or deal with the information. Many parents said they simply did not wish to burden their children with the knowledge that they were very sick and probably going to die. Others said that they feared the youth would inadvertently reveal the parent's HIV status to others, potentially resulting in discrimination toward the entire family.

Almost all the children who did know that their parent had AIDS had been told not to speak about it with anyone outside the family. In several cases, children whom we had been told knew about HIV in the family, told us that their parent had cancer. Even more striking was the fact that none of the adolescents who told us that they had a best friend, had told that best friend that their parent had AIDS. This was true even in a case in which a youth being interviewed knew that her best friend's mother also had AIDS.

Custody Planning

Custody planning represents an important step in a parents' acceptance of their illness and their ability to plan for their children's future. In the 20 closed cases, nine children were with grandmothers, seven with maternal aunts, two with fathers, and two with uncles. The myth that children of parents with AIDS are going into foster care was exposed in this study. Indeed, in the Division of AIDS Services 1500 families, less than 10% go into foster care.

In cases where the parent was still alive, the study found that there was no viable custody plan for 52% of the youth. Custody planning for older adolescents was particularly problematic, as their growing independence and "acting out" behavior made relatives reluctant to accept guardianship responsibility. For the purposes of the study, viability was defined as both the proposed guardian and the youth agreeing that they wanted to reside in the same household. Viability was loosely defined, because to do otherwise introduced ethnic and class biases, reflecting the researchers' expectations about the "proper" environment in which to raise children. For instance, viability did not take into account the guardian's health status, or whether the guardian had adequate financial resources to provide for the youth or enough space to easily accommodate sleeping arrangements needed for the additional household member.

Using our broad definition, a viable plan also might have a youth going to live with a relative who used drugs or an older sibling who had been previously in jail.

As a result, many of the custody plans judged viable by the researchers are, nevertheless, problematic. Adequate housing is particularly difficult to find and many of the families interviewed were living in crowded, sub-standard dwellings. In some families, children were sleeping in the living room, in the same bed with adults, or with different gender siblings or cousins. Among the other factors of concern when evaluating the viability of a custody plan are the short- and long-term health of the guardian, the guardian's previous experience in parenting adolescents, and the shared cultural values of the guardian and youth. In many cases, children go to live with a grandparent, usually a grandmother, following the death of their mother. These grandmothers are a diverse group, but few, if any, have anticipated playing such an active role in the raising of their grandchildren. Accepting children into their homes limits their participation in neighborhood churches and senior centers, isolating them from important social networks at a time when they may most need support. Grandmothers with chronic health problems or growing infirmities associated with aging, often neglect their own health needs, as their grandchildren's needs take precedence over their own. This is particularly true if one or more of

the children has HIV.

Differences in cultural values also may be an issue affecting the guardianship relationship between grandmother and grandchild. Many of the grandmothers interviewed had lived most of their lives overseas, often in rural areas, in Puerto Rico, Haiti or other Caribbean countries. Often they spoke very little English and had little contact with people outside their own family and ethnic group. The grandchildren they care for have lived all of their lives in the urban United States. They may not speak the native language of their grandparent's generation and almost certainly have different behavior norms and expectations. The potential for misunderstanding and conflict is great in these situations, especially at a time of loss when coping skills are already strained.

There were a number of custody plans that we thought were problematic because the guardian had no previous parenting experience, particularly experience with adolescents, either because they were very young themselves or had no children of their own. In a number of cases, minors were living with their older siblings or with very young aunts or uncles. These guardians are barely out of the teenage years themselves, and if they had children of their own they were very young. In several of the families interviewed and in countless others about whom we heard from case managers and other service providers throughout the

city, older adolescents were going to great lengths to try and keep all of their siblings together in one household. In some cases, this pits older adolescents against adult family members who may wish to take custody of younger children, but who have no interest in accepting the older adolescent into their home. In other cases, there was no other suitable adult to take custody of the children and the only other alternative for the younger siblings was foster care.

In families where there had not been complete disclosure, we often felt that the children who supposedly did not know that their parent had HIV had a strong suspicion or in fact did know. Some parents said they wanted to disclose their HIV status to their children, but did not know how to bring it up. Others told us that they simply could not bring themselves to tell their children they had HIV, because they believed it would change their children's perception of them. As the fact that they were ill became more difficult to hide, they told their children that they had cancer, kidney disease or some other chronic, serious ailment.

Informing their children about their HIV diagnosis was one of the most difficult tasks the parents we interviewed faced during the course of their illness. In cases where the parent had not informed the child, this task was one that the new guardian was left to wrestle with after the

death of the parent. In some cases, parents told us that disclosing their HIV diagnosis to their children had been a huge mistake. In one case, a mother who had disclosed on the advice of her hospital social worker, described her disclosure to her 18-, 15- and 7-year-old to be "like dropping a bomb with no plan for the clean up." In this family and others that we interviewed, the adolescents most frequently cope with the parents' illness through denial, refusing to discuss--directly or indirectly--related matters, such as future custody arrangements or anticipatory grief for their parents.

Coping Strategies

What are the coping strategies that hold families and individuals together? Sometimes these coping strategies can be both helpful and destructive. One example of this is denial of a terminal illness. Another example of this dichotomy is involvement in a church which simultaneously assists a grandmother in coping with her daughter's terminal illness at the same time that it perpetuates the stigma attached to AIDS.

Rosa and her family demonstrate how one family deals with coping and strength. Rosa--with her 31-year-old daughter--has been able to hold her family together--enduring the loss of her other daughter to AIDS.

CASE STUDY: Altagracia

Deceased Parent

Altagracia (Died 10/26/89) DAS client

Household Composition

Name	Age	Relationship to Client
Rosa	(72)	client's mother
Santa	(31)	client's sister and legal guardian of client's children
Orlando	(11)	client's son.
Milagros	(16)	client's daughter.
Maria	(7)	Santa's daughter.

Family Background

Rosa and Julio had seven children. Altagracia was the oldest and the only one born in Puerto Rico. Shortly after her birth, the family moved to New York. Her father, Julio, met another woman, left his family, and returned to Puerto Rico with his new lover. Rosa raised the seven children on her own. In 1972, her only son died of hepatitis.

Santa has lived with her mother all her life. She is a single parent with a daughter who is seven years old. Rosa and Santa moved into a new apartment in May 1989. The neighborhood was dangerous. Rosa and Santa wanted the apartment because it had enough space for the three of them and it is within walking distance of their extended family.

A month after Rosa and Santa moved to the new apartment, Altagracia became very sick. Initially, family members took turns visiting, cooking for her, and making sure Orlando and Milagros got to school on time. Altagracia's health deteriorated quickly. By the time her DAS case was opened, in August, she had been hospitalized once, and could no longer live on her own. According to Rosa, Altagracia wasted away. She had always been overweight, but in a matter of months she became thin and fragile. She could not keep food down.

Altagracia and her two children moved in with her mother and sister, Santa. According to Rosa, she was not told of her daughter's diagnosis until the final month of her life. The children were told by their guardian, Santa, following Altagracia's death.

Problems

Housing had been the family's biggest concern since Altagracia and her children moved in 1989. Witnessing the conditions this family has been living under, and feeling unable to significantly change their situation, stirred up feelings of impotence and futility in the case manager. These feelings have been particularly strong in this case because this family has done everything they possibly could to help themselves.

There were 5 people in the household--representing three generations--living in a one bedroom apartment. Rosa, Santa and Maria shared the bedroom. Santa and Maria shared a twin bed. Overcrowding is only one of their housing problems. The building is filthy and rat-infested. It is unsafe because the lobby entrance is never locked. The stairs leading to their third floor apartment are weak and hazardous.

During most of the winter the building had been unheated. The family had to boil water to bathe. Several times during winter the landlord left the country without paying the fuel bill. The landlord was out of the country and could not be reached. Tenants were forced to wait in their cold apartments for the landlord to return. When we last visited the apartment, the family was without water in the apartment and using the nearest fire hydrant as a source of water.

Meanwhile, the landlord repeatedly threatened to evict the family. He claimed that he rented the apartment to three people and there were five people living there. He considers this a violation of the lease agreement. He has even also attempted to raise their rent, but failed because the lease is in Rosa's name and she is a senior citizen.

Everyday, Santa goes to the church on the corner where she attends services and does volunteer work. The church is her mainstay of hope. She prays that her family will be cared for and she prays for a new place to live.

Significant health issues were being neglected due to the family's pronounced need for adequate housing. For example, Rosa's health is very poor. She has glaucoma, which has progressively weakened her eyesight. She has lost all hearing in one ear. She is also extremely depressed, and may be medicating herself with alcohol and anti-anxiety medication given to her by a friend. She told the interviewer that she gets through difficult moments by not thinking about Altagracia's death and by taking an occasional shot of rum.

Milagros also seems depressed. Santa and Rosa have noticed she has withdrawn, and shows no interest in most things. Some mornings she has difficulty getting out of bed to go to school. Santa and Rosa are worried about her. However, they are reassured by her academic performance

which remains excellent. Santa is considering counseling for Orlando, who they say seems distracted and has frequent tantrums.

In December, 1991, they received some truly wonderful news. Rosa and Santa were able to find a new apartment through the New York City Housing Authority. The apartment is more spacious, cleaner, and safer than their former home.

Summary

This is a family with resources, a support system and the ability to use their environment effectively. At our first meeting, after discussing the housing problems, we offered some ideas and arranged to help them with the application for public housing. A month later, Santa called to say that the housing authority invited them to an interview appointment. She asked the researcher to come along in case she needed help. She handled the interview very well on her own. Rosa and Santa were also able to find a summer camp for Orlando and a summer job for Milagros without our help.

They are also able to interact with sources of support within the community. They have established credit with the corner grocer. This is helpful when the family is low on cash. Similar relationships have also been created with the local church and other sources of support within the community. The extended family is also accessible and very supportive.

This family was able to use informal and formal resources. However, since DAS cases are closed when the sick member dies, the surviving members of the family are not DAS clients and accessing services becomes almost impossible. Family members are basically on their own at a time of crisis, and many important issues are not addressed. Housing has not been the only issue in this family, but it has been so overwhelmingly inadequate, that it casts a shadow over every other single aspect of family life. The other concerns such as bereavement, health, employment and education could not be effectively addressed until the housing problem was addressed.

This case is an example of a family who manages effectively in a crisis.

Rituals can and do provide healing for many families. Rituals may be religious, or spiritually based or part of a family's collective experience. Both planning and executing the ritual is important to the family unit. Rituals

described in the study included Sunday family dinner, holiday picnic outings, church attendance, or gathering to watch a weekly television show. One of the difficulties expressed by children was that the illness of the parent had "changed everything". Rituals--when they could be continued--helped children to feel more grounded.

The spiritual aspect of life is very personal and is often greatly affected by one's ethnic perspective. Spirituality affects attitudes toward death and dying, and the future. Families facing death have unique ways of expressing pain and grief. Families also differ in their expectations of family responsibility and their acceptance of outside assistance and/or authority.

It was impossible to generalize ethnic responses to any of these tasks or to coping strategies of the families. Even though all the families in the study were Hispanic or African American, the researchers did not observe differences in the ways family cope. Each time we saw two families with a similar response or coping style, a third and fourth family with common ethnic heritage differed. Each family member's expression of grief was so individual that making comparisons within diverse cultural populations was not possible.

Client Power

Adversity has brought many of the families in this study closer together. The adolescents are painfully aware of how little family they have left and their dependence on them to be taken care of. The plight of families to keep the HIV secret within their families is related to both the fear of discrimination and "keeping the family honor".

In Families Facing Death (1990), Rosen says that regardless of ethnicity, a woman nearly always assumes primary caring responsibilities. He states:

> "Whether she was the wife, daughter, daughter-in-law, mother, sister, grand-daughter--even when she was the patient--her active presence was vital to family functioning.

Grandmothers and maternal aunts are some of the heroes of the AIDS epidemic. A few of these grandmothers have asked, "Where are my golden years?" (Pearson, 1992). But almost all have forged ahead providing the only remaining glue in the family. Because of their commitment to family, particularly to children, stability and structure continue to exist. Meals get cooked and children are fed, homework is checked, relatives are called and outings are planned. When asked to name their source of strength during periods of loss and turmoil many of them replied without hesitation that their strength lay in their profound faith in God--a God they turned to in times of great sorrow. When everything around them was filled with loss, their God was a

constant comfort. As pillars of strength within the family, it often seemed that these women could not allow themselves to grieve at home. Church for some was the only place they could go to openly grieve.

For others, particularly soon after the death or in families with multiple AIDS deaths, the grief was so overwhelming and the emotions so uncontrollable that going to Church was like opening the flood gates. One woman who had just lost a sister, had another with full blown AIDS and a brother who had just been diagnosed HIV+, told the interviewer that she could not go to church anymore. The few times she had gone after her sister's death she became hysterical, and practically had to be carried out of church.

Very few families had shared that AIDS was in the family with fellow parishioners or the priest or pastor. Sometimes painful ironies were presented. For instance, a man with AIDS and his wife were active members of a Pentecostal church which as part of its outreach program visited people with AIDS in the community hospital. In this family's case the church was so important to them that they could not risk losing the support as a result of disclosure.

Sometimes there was one person, usually another woman their age, who did know and was a good friend and companion. In one case, there was a support network for families with AIDS that met in members' homes.

Conclusion

The case study of Annie and the data regarding denial, disclosure and custody planning illustrate one of the main problems that all families with AIDS must confront. Each family--and each family member--must call upon inner resources to recognize, label and acknowledge the existence of AIDS and death. Most adolescents and adults in close proximity to the mother with AIDS have questioned themselves about whether or not the illness might be AIDS. But each person has chosen to cope with this question and whether or not to get it answered in a different way.

It is important for friends, neighbors and professionals to respect the decisions made by each person. The research team concludes that each family must decide what is best for them. The professional inclination to encourage disclosure must be held at bay. After hearing of the consequences of individual disclosure, it is important for clients to weigh the alternatives. It is also essential for professionals and parents to carefully examine the context and tools which the family possesses before making the disclosure option part of the therapeutic process. Dealing with stigma and death is a difficult task for both the families and the professionals.

Rosa and her family demonstrated the coping strategies of one family dealing with AIDS. They used inner and outer

resources to amass a kind of client power which was reflected in many families in the study. With formidable tasks such as HIV disclosure, custody planning and preparing for death, they were able to use self, family, church and community resources to provide strength in living with AIDS. As Ernest Hemingway said, "The world breaks everyone and afterward some are strong at the broken places".

CHAPTER SIX

CONCLUSIONS AND PRACTICE IMPLICATIONS

Introduction

The families in this study function along a set of continua from desperation to hopefulness and from helplessness to self-sufficiency. While many families interviewed in this study showed remarkable reserves of strength and demonstrated an unusual ability to rally in the face of profound difficulties, progressive illness inevitably places great strain on the coping skills, already fragile in families with AIDS.

Each stage of HIV infection, as well as death itself, presents the adolescent and the family with new tasks and problems. When first accessing the Division of AIDS Services, many clients and their families are just beginning to address health concerns including disclosure of serostatus, risk acts, and access to health care. Usually about six months after entering the Division, family issues such as custody planning and coping with death and dying begin to be of primary importance. After the family member's death, adolescents and the other surviving family members must grieve the loss of the parent, work out new

family relationships and start a new life.

This chapter identifies the primary needs of adolescents in families with AIDS and discusses how services can be designed to bolster family strength and provide more social supports to these youth.

The statistical projections for New York City and the rest of the country indicate that there will be many more children and youth in need of homes and support services than are now being provided by a social service establishment that is already overwhelmed by the breadth, depth and complexity of need. The societal, community, family and personal issues all impact on whether our young people will mature into fully productive adults. The service strategies must address the concerns and needs of specific communities at the same time as they are recognized as essential components of a comprehensive national strategy to support families and communities ravaged by HIV infection and AIDS.

The Need for Supportive Counseling and Advocacy

The overall experience of interviewers was that the families they spoke with had a great deal to say and wanted to talk with someone ready to listen. A ten-year-old boy who had just lost his mother wanted to talk about how important it was to do well in school because it was his

mother's greatest wish to see him graduate from high school. He said, "I missed a lot of school when she was sick, but now I'm going to study hard and make her proud." A 14-year-old Bronx girl expressed her desire to go to a support group of young people who had recently lost parents--one of the only groups available for youth in New York City--and of her frustration in being unable to because she was too young to travel by subway to Manhattan.

Yet despite this responsiveness to interviewers, most of the family members interviewed had virtually no one else with whom they discussed their losses. Not one child had told a best friend that a family member had AIDS. And, as mentioned earlier, in an example tinged with irony, a man with AIDS and his wife were active members of a church group visiting hospital patients with AIDS; nevertheless, they felt that to disclose his HIV status would risk losing vital church support, and so they chose not to share this information even with these fellow parishioners.

In the majority of these families, then, there was no supportive structure for bereavement or healing. Our research strongly suggests that families could benefit from a variety of innovative programs to address their needs.

Family members need ways of talking to others like themselves that protect their identity and avoid the problems associated with transportation (lack of and/or inability to access) in both urban and rural areas.

Telephones and computers are two readily available and relatively inexpensive ways of connecting people that need to be explored. Several computer networks for youth are currently operating in New York City, and researchers at the National Cancer Institute have been evaluating the effectiveness of time-limited telephone groups comprised of people from around the country. Both of these methods, telephone networking and computer linkage, hold promise for breaking down the barriers that isolate people with AIDS and their families.

Some service project ideas and grant applications have come out of the youth study. The following is a list of possible new projects which will be discussed in greater detail below:

- School and court advocacy
- Legacy video project
- Grandmothers' support network
- Youth computer networking
- Bereavement services
- Family reunification
- Ongoing family case management
- Clergy Outreach
- Prevention education for teens

SCHOOL AND COURT ADVOCACY - To provide specialized counselors to address school and court problems of youth in families with AIDS.

The youth interviewed in this study needed advocates in the school system and the court system. Many youth would benefit from advocacy assistance even on an occasional basis. This is particularly true of youth in families plagued by drug use, illness and unstable living situations. These adolescents are unlikely to have family members who are willing or able to advocate for them. Relatives who work in marginal jobs are unable to take time off to investigate a problem. Relatives may be intimidated by the system and easily frustrated by the many bureaucratic snags that will inevitably impede their ability to solve problems. In addition, family members may not always be the young person's strongest or best advocate. Adolescents with behavior problems that have gotten them in trouble at school or with the law are probably exhibiting similar problems at home. Parents and family members may have ambivalent feelings about what should be done and often feel at a loss about how to impose discipline at home. In some cases, families may feel that the school or the court system is the only place where youth are going to be exposed to the disciplinary action they really need. Advocates are

particularly important for these youth, both to assist in solving the immediate problem at hand and to be available to provide ongoing support. In many cases, school advocacy is needed to guide a youth through investigation and decisions about alternative educational settings. Some of the youth we interviewed were choosing to attend GED programs rather than finish high school. The choice to pursue a GED was made because the rigidity of the school schedule did not allow them to be at home with a sick parent or to work. In some cases, particularly with older teens who had assumed a great deal of responsibility in the home during the parent's illness, a GED was chosen because it was very difficult for them to accept the traditional student role.

School advocacy must also include access to tutoring and special assistance in test-taking. New York City has a system of specialized, competitive high schools to which a number of the youth we interviewed were interested in applying. These students need assistance in determining which schools are the best choice for them and coaching on how to prepare for the entrance exams. In most cases, their parents had no idea of how to assist them and the guidance staff is in general not able to provide the type of short-term intensive assistance these youth require.

LEGACY - To provide DAS clients with an opportunity to make a videotape to be left as a legacy to their children.

Through this project, parents with AIDS can learn more about themselves and also leave a meaningful and lasting gift to their children. The project budget consists of video equipment costs, editing fees and salary for a social worker to assist clients in planning, taping and editing their legacy.

GRANDMOTHERS' SUPPORT NETWORK -To build support networks among grandmothers who are guardians of children and youth who have lost their parents to AIDS.

These grandmothers are often isolated by their grief, by the stigma of having AIDS in the family, by their own chronic health problems, and by the responsibility and energy required to make a home for children, some of whom may have HIV. The project budget consists of the salary for a social worker to recruit grandmothers into telephone and face-to-face support groups and to facilitate the groups once formed. Monies for transportation and telephone service are additional budget items.

YOUTH COMPUTER NETWORKING - To build upon an already existing youth computer network and bulletin board in New York City, improving its relevance and accessibility for youth in families with AIDS.

Computer networking provides youth with an anonymous forum for communication, where they can share information and feelings with peers and counselors and can access information about educational and work opportunities, AIDS prevention, and other salient topics. The project budget consists of a salary for a network coordinator, and computer hardware costs for expansion of the network to community sites in the outer borough neighborhoods where most families with AIDS reside.

BEREAVEMENT SERVICES - To provide short-term, in-home counseling services to families experiencing AIDS-related losses, with a focus on stabilizing families and ensuring that families' ongoing mental health needs can be met by referral to community-based mental health providers.

Many families are open to the idea of counseling but experience multiple obstacles to accessibility to services, including fear of the mental health system, unavailability of transportation, ethnic and language barriers, and long waiting lists for services at community mental health

centers. This project budget consists of the salaries of two bilingual (Spanish/English and Creole/English) social workers with bereavement training to do short-term work with families and to follow up on referrals to community services. Monies for transportation are additional.

FAMILY REUNIFICATION - To assist women with AIDS who have a history of current or past drug use, and whose children are in foster care, to re-establish relationships with their children.

Women who are current or past drug users often have had some or all of their children placed in the foster care system; in some cases they have lost track completely of their whereabouts. This project consists of the salary for a social worker to assist mothers in finding and contacting their children and in re-establishing relationships, when mutually agreed to by the foster care family and agency.

ONGOING FAMILY CASE MANAGEMENT - To provide intensive one-stop entitlement and social services to families with AIDS in order to help all those in the household to cope with illness and loss.

Most families with AIDS are barraged by a number of problems which began before AIDS and will likely continue

long after the person with AIDS has died. Case managers with adequate training, support and small case loads are necessary to assist families with a complicated and fragmented social and health system.

CLERGY OUTREACH - To provide training and support about families with AIDS to clergy members so that they can increase their support to parishioners and members of their community.

Many of the family members were connected to their churches and found comfort in their spiritual values. But none of the families felt safe enough to share the burden of HIV disclosure with their clergy or fellow parishioners. There is work to be done with the clergy and with the church to stand as a model of understanding and compassion for all its people. Since many minority family members experience the church as the only community organization to which they can turn to for help, it is important for the churches to be ready to serve them. In addition, loss and death lead people to their own spiritual search as well as formal religion and rituals. The church is an important resource for families with AIDS and could expand its commitment and scope of service with education and support.

PREVENTION EDUCATION FOR TEENS - To encourage teens at great risk for HIV to take responsibility for their behavior and take a pro-active stance on behalf of their own health.

The adolescents in this study did not make the connection between their parents dying of AIDS and risk behaviors in which they themselves were participating. There is significant research on adolescent pregnancy which demonstrates the invincible feelings of many adolescents. It is a mistake to believe that watching a parent die of AIDS in one's own home will have an impact on prevention knowledge or behavior. It is necessary to address the topic of safe sex practices and to involve teens in programs which support their exploration of attitudes, beliefs and actions.

Policy Implications

This study reflects the growing and complex problems of youth growing up in families with AIDS. As the population with AIDS continues to grow, services for families will need to be expanded. At the Human Resources Administration, demonstration funding provided enhanced services to three hundred families with AIDS. This, however, represents less than 30% of the total number of families within HRA's Division of AIDS Services. Specifically, if a woman with

HIV who has children goes to an Income Support Center for public assistance and Medicaid, her worker will have up to 170 cases. Individual attention is clearly impossible. If a woman with AIDS goes to the Division of AIDS Services and is in the generic unit, her worker will have up to 33 cases. If a woman with AIDS is part of the HRA's specialized AIDS family program, her worker will have up to 15 cases as well as the support of a social worker, nurse, and child welfare liaison.

This study defines the needs of parents and adolescents. Small case loads are absolutely essential in order to work with all family members and help each of them to support one another. Dealing with denial, stigma, loss, disclosure, and custody planning takes time and trust. Demonstration programs provide important information, but not the funds to institutionalize the services needed.

As a society, we continue to "target" services to individuals instead of looking at the whole family. This is partially explained by the lack of necessary financial resources. It is partially due to the existence of different funding streams for different problems. The AIDS crisis dramatically exposes the weaknesses in health, medical, and social service systems. Furthermore, it highlights the ways in which these systems do not coordinate with one another.

Society will be expected to pay for services to these

children now or later. For example, loss and trauma not dealt with constructively now will likely result in truancy, or even jail, later. This study has demonstrated the need to invest in these adolescents now.

Currently, most custody plans name the grandmother or maternal aunt as the future guardian. The generation of grandmothers who are raising grand and great grandchildren is aging and getting sicker. Without them, foster care and adolescent home options must be re-examined and reinforced. Creating strategies that will provide safe homes in which these adolescents can choose school, work and hope over pregnancy, drugs and violence is essential for everyone's well being.

Suggested Areas For Further Research

In the coming years many thousands of children will need loving, stable homes. As the epidemic continues to stretch the resources in the communities most ravaged by the virus, grandmothers and aunts may no longer be able to continue as the heroines. What other homes can be found? How can the foster care system get ready for this influx?

We do not know how to best serve parents with AIDS and their children. Studies which measure the results of different interventions need to be funded and conducted.

We do not know how to assist families with the dying

process. We do know that it is not in a far-away office with a professional psychotherapist who sees patients for regularly scheduled fifty-minute appointments. Families with AIDS need in home services - for convenience, for reducing stigma and for privacy.

We need to know more about how to best serve parents with AIDS and their children. In order to do so, findings of this study suggest that research is needed in several different areas:

* Can studies which measure the results of different interventions be funded and conducted to address the best way to assist a family with the dying and grieving process?

* How can we most successfully achieve long-range planning of foster care for the future influx of orphaned children? Are there other mechanisms such as group homes that should be explored for adolescents?

* How can we do a longitudinal study to follow well adolescents in families with AIDS in order to understand the long term ramifications of experiencing devastating loss?

* We do not understand the family dynamics of custody planning. What enabled half the families to prepare a future for their children? What are the interventions which might have helped the other fifty per cent of parents who died with no custody plan in place for their adolescent children?

* What is going to happen to the many children who have never been told that their parent(s) died of AIDS? Will they put the clues together later, and what impact will this have on their development?

* Is their a relationship between disclosure and depression for the parents and/or for the teens?

* What are the effects of disclosure and non disclosure on custody planning?

* How would families with AIDS score on measures of religiosity and how can we use this information to assist them?

This study has provided insights we think are useful in beginning the development of new strategies to support families and adolescents affected by this epidemic. But we need the answers to these questions in order to fully attend

to the needs of families with AIDS, and we need substantial rather than piecemeal funding in order to do it.

Priorities for the Future

The forty families we interviewed had extraordinary reserves of strength and power. Single mothers coping with their own terminal illness demonstrated enormous care and compassion for their children. Family members, particularly the mothers and sisters of the women with AIDS, were often the "glue" holding their families together. With AIDS in some communities taking the lives of an entire generation of young parents, it was not unusual to interview a grandmother or an aunt caring for more than one daughter's or sister's children. There is much work to be done in communities most affected by the epidemic. Families with AIDS need to see themselves in a larger context and reduce the stigma of feeling that they are alone.

Amidst enormous loss, these families moved forward with a strong positive spirit. In the second decade of the AIDS epidemic, we must broaden our focus to include those left behind after the death of a person with AIDS. Adolescents in families with AIDS are among our most vulnerable populations. Individual, family, group and community interventions are needed to assist them in addressing their losses and creating their futures.

APPENDIX 1

Invitation Letter

Ms. Judy Jones
2 South Street
Brooklyn, N.Y. 10000

March 4, 1991

Dear Ms. Jones:

We are writing to invite you to speak with us about your family's experiences. We are especially interested in speaking with you about how things have been going since you became ill. We also would like to speak with Jake and Susan about their experiences.

Our interview with you is part of the Youth Counseling Project. We believe that families know best what they need. In order to develop the best services possible for your family and others, we hope to ask questions of you, Jake and Susan.

We appreciate your help very much. To thank you for giving us time with this very important project, we will be providing families who participate with movie tickets at the end of the interview.

If we do talk, everything we talk about will be private. If you decide not to speak with us about your experiences, it will in no way affect your current benefits.

We would like to speak with you first and then speak with Jake and Susan. Our interview with you will probably take about three hours. The time and place will be set at your convenience, and can be on an evening or weekend at your home, if you wish.

We will be calling you to know your decision early in the week. If you have any questions which you would like answered before you make a decision, please feel free to call us at (212)966-8112.

Sincerely,

Barbara Draimin, CSW Jan Hudis, MPH José Segura, CSW
Coordinator

B.Smith
4 Rock Lane
Brooklyn, N.Y. 11418

March 4, 1991

Estimada Senora Smith,

Le estamos escribiendo para invitarla a hablar con nosotros sobre las experiencias de su familia. En particular nos interesan los cambios que an ocurido en su hogar desde la muerte de Gladys.Ademas,deseamos hablar con Crissy y John sobre el efecto que la enfermedad y muerte de un familiar a tenido en sus vidas.

Nuestra conversation sera parte de el Youth Counseling Project (Proyecto de Consejeria Adolescentes). Con este proyecto deseamos desarollar los mejores servicios posible para familias como la suya. Creemos que familias tienen un conocimiento de sus necesidades que es profundo y valuroso. La participation de su familia seria una gran ayuda a nuestro objectivo.

Como gracias por su ayuda queremos ofrecerle a todas las familias participantes boletos de cine al final de la entrevista.

La entrevista sera totalmente privada y si usted decide no hablar con nosostros sus beneficios no seran afectados en ninguna manera.

Durante la entrevista desearemos hablar con usted antes de hablar con John y Crissy. Al final tendremos la oportunidad de reunirnos y hablar. La entrevista tomara aproximadamente dos horas. La hora y lugar de nuestra cita sera a su conveniencia.

Al principio de la proxima semana la llamaremos para saber su decision. Si prefiere,puede responder por coreo usando el sobre que vino con esta carta. Si tiene algunas preguntas,las cuales necesitan respuesta antes de tomar su decision,nos puede llamar al 1.212.966-8112

Sinceramente,

Barbara Draimin, MSW Coordinator Jan Hudis, MPH José Segura, CSW

APPENDIX 2

Consent Form

Consent Form

Title of the Project: Youth Counselling Project

Interviewer(s): Barbara Draimin, Jan Hudis, Jose Segura

We agree to participate in the "Youth Counseling Study" being conducted under the auspices of the New York City Human Resources Administration. If I believe I have any problems as a result of my participation in this study I should contact Terry Mizrahi at the Hunter College School of Social Work (212) 452-7112.

We understand that the purpose of the project is to learn how young people 10-19 years old and their families sort out their feelings and reactions to the illness and potential loss of a parent. We understand that the survey is being conducted in order to find out what kinds of services are needed by our family and others like it in order to make this time easier for all of us. The survey will include questions about family coping skills, use of services, acting out behaviors and sex and drug usage. Specifically:

1. In this project, parents, guardians, and adolescents will be asked questions by the interviewer and also given written questionnaires to complete.

2. Participation in this study is voluntary and will not affect entitlement benefits in any way.

3. It is understood that a family's agreement to participate does not obligate us to answer questions which are found to be uncomfortable. We understand that we can withdraw from this study at any time, even after beginning.

4. It is agreed that the names of family members will remain confidential with regard to any publications and presentations of the results. Records in this study will be kept confidential to the extent permitted by law. The interviewers are required to report planned injury to oneself or others as well as child abuse and neglect.

5. It is understood that our family will be given movie tickets to say thank you for our time.

6. All questions concerning the study have been answered to our satisfaction. We understand that any questions we may have in the future will also be clearly answered by the interviewer.

Signature of Subjects: _____

Date: _____

APPENDIX 3

Case Interview Tools

OPEN CASE INTERVIEW PROTOCOL

1.1 We are interested in the things that have been happening to you and your family in the past year. Some of these things happen to many people, some happen to only a few.

During the past year what changes have taken place in your life?

1.2 People react differently to changes in their life. Of the changes you have been through in the last year, which have been the most difficult for you? Why?

1.3 Now, I would like to ask a few specific questions about things that may have happened **(since _____ became ill).**

(Interviewer: Change to (in the last year) if child does not know parent is ill or parent if family doesn't acknowledge illness)

		Since Illness (In the Last year)	
		YES	**NO**
A.	Did you start going to a new school.....	Y	N
B.	Did you move to a new neighborhood.....	Y	N
C.	Do you spend less time with your friends because of increased responsibility at home..	Y	N
D.	Has anyone you are close to or like a lot become more difficult to see or talk to because they moved away, got a new job, had a falling out with your family, etc.....	Y	N
E.	Did you have a major illness or serious injury.....	Y	N
F.	Do you worry about your own health.....	Y	N
G.	Has a family member had a serious injury....	Y	N
H.	Do you worry about the health of other family members.....	Y	N
I.	Have you been suspended from school or dropped out.....Y		N
J.	Have you gotten into trouble at school for talking too much, skipping class, fighting, having a weapon, stealing or other problems.....	Y	N
K.	Have you gotten recognition for something you had done in school or in the community.....	Y	N
L.	Did you get a job.....	Y	N
M.	Did you lose a job.....	Y	N

	Since Illness (In the Last Year)	YES	NO
N.	Has a close friend or family member attempted or commit suicide.....	Y	N
O.	Have you been in a big physical fight.....	Y	N
P.	Have you or someone in your family been robbed or attacked.....	Y	N
Q.	Have you joined a gang or been pressured to join a gang.....	Y	N
R.	Have you stolen or destroyed property.....	Y	N
S.	Have you seen any person or animal get hurt in a way that really upset you.....	Y	N
T.	Has anyone made you do something that you felt bad about afterwards.....	Y	N
U.	Have you lived in the same house with someone who drank too much.....	Y	N
V.	Have you lived in the same house with someone who took drugs not prescribed by a doctor....	Y	N
W.	Have you failed any subject in school.....	Y	N
X.	Have you had changes in your eating habits or weight.....	Y	N
Y.	Have you had changes in your sleeping, not being able to go to sleep or not being able to wake up.....	Y	N
Z.	Have you had to stop doing things that you really like to do because of increased responsibility at home.....	Y	N
AA.	Have you started a new relationship with a boy friend or girlfriend.....	Y	N
AB.	Have you broken up with a boyfriend or girlfriend.....	Y	N
AC.	Has a close friend or relative gotten very sick or died.....	Y	N
AD.	Have you felt physically threatened in school or in your neighborhood.....	Y	N
AE.	Have you been arrested or had trouble with the law.....	Y	N
AF.	Has a family member been arrested or had trouble with the law.....	Y	N
AG.	Have you or a family member spent time in jail.....	Y	N

AH. Has anything else happened recently that you think was really important..... Y N

(IF ANSWER TO AH IS "NO", SKIP NEXT QUESTION)

AI. If "yes": What were the events and when did they happen?

Interviewer: Probe any "YES" answer for events listed above.

When did it happen?

Please tell me briefly about it?

A. Event # _____
Date: __ __/__ __/__ __
Event description:_____
_____

B. Event # _____
Date: __ __/__ __/__ __
Event description:_____
_____

1.4 I would like to ask you a few questions about things that may be worrying you now. Some of these things may have worried you before, and I would also like to know that.

N=Never R=Rarely S=Sometimes O=Often

		N	**R**	**S**	**O**
A.	Are you concerned about your health.....	0	1	2	3
B.	Were you concerned about your health before.....	0	1	2	3
C.	Are you concerned about _____'s health, his/her eating etc.	0	1	2	3
D.	Are you concerned about money problems....	0	1	2	3
E.	Were you concerned about money before.....	0	1	2	3
F.	Are you concerned about your brothers' and sisters' health, eating, homework	0	1	2	3
G.	Were you worried about your brothers and sisters before (_____ got sick).....	0	1	2	3
H.	Are you concerned about missing too much school or doing poorly in school.....	0	1	2	3
I.	Do you worry about where you may be living or who you may live with in the future....	0	1	2	3
J.	Are you concerned about other people finding out that _____ is sick	0	1	2	3

K. Are you concerned that others in the family might not be able to handle the stress of_____'s illness 0 1 2 3

L. Do you worry now that other people in the family are depressed 0 1 2 3

M. Are there other things that you are very worried about 0 1 2 3

(IF ANSWER TO N IS "RARELY" OR "NEVER", SKIP NEXT QUESTION)

N. If "sometimes" or "often": What else were you very worried about when _____ was sick?

1.5 Thinking about what is happening in your life right now, can you tell me what are your biggest worries?

1.6 Do you have thoughts that keep you awake at night or make it hard to concentrate in school?

no.....0
yes.....1

If "yes": What are they?

Often when someone in the family is ill, other family members take on more responsibility for chores in the house. Sometimes they spend a lot of time taking care of the person who is sick.

(Interviewer, if child doesn't know parent is sick change to: Often things in a family change, making it necessary for some family members to take on more responsibility at home.)

1.7 Have you recently had to do more things around the house and for the family ?

no.....0
yes.....1

If "yes", What kinds of things are you doing?

1.8 Now, I would like to ask you some specific questions about things you may be doing around the house.

		N	**R**	**S**	**O**
A.	Do you go shopping for food or other essentials	0	1	2	3
B.	Do you go to the drugstore or clinic to get medicine for _____ or anyone else in the house	0	1	2	3
C.	Do you go to the clinic with _____ or anyone else in the family	0	1	2	3
D.	Do you make phone calls or keep appointments with city agencies or others who are involved with your family	0	1	2	3

E. Do you try to find help for anything related to what is happening in your family.....0 1 2 3

F. Do you do laundry 0 1 2 3

G. Do you take care of your brothers and sisters.....0 1 2 3

H Do you cook meals.....0 1 2 3

I. Do you clean house.....0 1 2 3

J. Do you take care of _____, making sure he/she eats, takes medicine, or goes to the clinic.....0 1 2 3

K. Do you ever stay home because you are afraid that _____ might need you....0 1 2 3

L. Are there other responsibilities that you have taken on in the last few months.....0 1 2 3

(IF ANSWER TO L IS "NEVER" OR "RARELY", SKIP NEXT QUESTION)

M. If "sometimes" or "often", what other responsibilities have you taken?

1.9 Can you estimate how many hours a day you spent doing all of these things in the last two months?
_____hrs/day

1.10 Has the amount of time that you spend doing things in the house changed in the last six months?
no.....0
yes.....1

If "yes": How has it changed?

1.11 How much time did you spend doing these things a year ago?

_____hrs/day

1.12 Does anyone else help in the house (or help take care of _____ when he/she is sick)?

no.....0
yes.....1

If "yes": Who helps, what do they do and how often and how long are they in the house?

1.13 Could you and your family use more help?

no.....0
yes.....1

If "yes": What kind of help could you use?

1.14 Has anyone in your family been in the hospital recently?

no.....0
yes.....1

(IF NO, GO TO QUESTION 1.21)

1.15 Where was _____ hospitalized? For how long?

1.16 Where did you stay during that time?
(Who was taking care or you?)

1.17 Did you get a chance to visit _____ in the hospital?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 1.18)
(IF "NO", GO TO QUESTION 1.19)

1.18 If "yes": How often did you visit? How did you get there?

(GO TO QUESTION 1.21)

1.19 If "no": Can you tell me why you did not go to the hospital?

1.20 Would you have liked to visit _____ in the hospital?

no.....0
yes.....1

(IF CHILDREN HAVE NOT BEEN SPLIT INTO DIFFERENT FAMILIES AND HAVE NOT MOVED TO NEW NEIGHBORHOODS OR SCHOOLS, GO TO SURVEY INSTRUMENTS)

(IF CHILDREN HAVE BEEN SPLIT UP INTO DIFFERENT FAMILIES, GO TO QUESTION 1.21 NEXT)

(IF CHILDREN HAVE NOT BEEN SPLIT UP BUT HAVE MOVED TO NEW NEIGHBORHOODS OR NEW SCHOOLS, GO TO QUESTION 1.30)

(FOR CHILDREN WHO HAVE BEEN SPLIT UP INTO DIFFERENT FAMILIES)

Sometimes children go to different families when a parent is sick. Sometimes brothers and sisters may not get to see each other very often and sometimes when they do the visits can be hard.
(Interviewer: change wording depending on family circumstance)

1.21 How far away does _____ live now?

1.22 Do you see each other?

no.....0
yes.....1

(IF YES, GO TO QUESTION 1.23)
(IF NO, GO TO QUESTION 1.25)

1.23 If "yes": How often and for how long do you see each other?

1.24 How do you feel about the amount of time you spend with _____ and how you spend that time together.

Would you say you are.....

very satisfied.....1
satisfied.....2
somewhat satisfied.....3
not satisfied.....4

How would you change the way you spend your time together?

(SKIP NEXT QUESTION)

1.25 If "no": Why you don't see each other?

1.26 Do you talk on the phone with?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 1.27) (IF "NO", GO TO QUESTION 1.28)

1.27 If "yes": How often do you talk on the phone?

(SKIP NEXT QUESTION)

1.28 If "no": Why don't you talk on the phone?

1.29 Is there anything that you wish could be different about your relationship with _____ right now?

no.....0
yes.....1

If "yes": What do you wish could be different?

(IF CHILDREN HAVE MOVED TO NEW NEIGHBORHOODS OR NEW SCHOOLS, GO TO QUESTION 1.30)

(IF CHILDREN HAVE NOT MOVED TO NEW NEIGHBORHOODS, GO TO PRETESTED SCALES)

1.30 Did you know anybody in the neighborhood before you moved here?

no.....0
yes.....1

If "yes": Who did you know?

1.31 How difficult has it been for you to make friends here? Would you say it has been.....

very difficult _____1
somewhat difficult _____2
fairly easy _____3
very easy _____4

(IF IT HAS BEEN FAIRLY OR VERY EASY, SKIP NEXT QUESTION)

1.32 Why do you think it has been difficult for you to make friends here?

1.33 What do you like most about your new neighborhood (school)?

1.34 What do you like least about your new neighborhood (school)?

Children's Depression Inventory, State Trait Anxiety Inventory, Self-Esteem Index and Family Hardiness Index

Now I would like you to take a few minutes to answer some questions about how you have been feeling lately and about how you and your family deal with emotions and problems. These questions are arranged in four sets. You may answer these questions on your own or we can do them together. Please take a look at this first questionnaire and tell me what you prefer.

Index

Self-Esteem Index

Family Hardiness Index

State Trait Anxiety Inventory

Children's Depression Inventory

PLEASE NOTE

174-175, Rosenberg/Hyler Self Esteem Items
176, Family Hardiness Index
177, State Trait Anxiety Index for Youth 13 and Older
178, State Trait Anxiety Index - For Youth 12 and Under
179-181, Children's Depression Inventory
M. Kovacs

Follow-Up to the Inventories

2.1 Families can react in many different ways to change, (such as someone becoming sick). Sometimes the family falls apart, sometimes people in the family become closer and stronger than they were before. Sometimes both happen. What has happened in your family?

(Interviewer: Probe for acknowledgement of parent's illness, if appropriate)

2.2 Has anything happened or have you noticed anything that makes you worry about _____?

no.....0
yes.....1

If "yes", what happened or what have you noticed that makes you worry?

(SKIP QUESTIONS 2.3-2.7 IF NO MENTION OF ILLNESS)

2.3 How did you find out for sure that _____ was ill?

2.4 When did you find out?

2.5 What kind of illness does _____ have?

2.6 How serious is _____'s illness?

2.7 What did you do when you first realized that he/she might get very sick from the illness?
Have you talked to anyone about it?

2.8 People have different people they count on for things. These people can be family, relatives, teachers, friends, people in the neighborhood and others.

A. Who do you feel you can really count on to cheer you up when you feel bad?.....Anyone else?

B. Who do you feel you can count on to take care of you? .....Anyone else?

C. Who do you feel you can really count on to help you when you need help? .....Anyone else?

D. Who do you feel really cares about the way you are thinking and feeling?.....Anyone else?

INTERVIEWER: For people listed by child, ask:

For Person 1:

1. How do you get hold of _____ when you need them?

2. How many times in the last 2 months would you say _____ has (cheered you up, taken care of you....)?

3. Can you stay with _____ if you need to?

For Person 2:

Same

2.9 Do you stay overnight at other people's houses?

no.....0
yes.....1

If "yes": Whose house do you stay in? How often?

2.10 Where do you go after school? (If not home, ask where respondent goes, how long he/she spends there, and how often he/she goes. If home, ask who's generally at home when they arrive.)

2.11 Who do you call in case an emergency comes up at school?

2.12 Who do you call in case an emergency comes up when you are home alone?

2.13 How many friends do you have?

2.14 Has your number of friends changed in the last six months, (since _____ became ill)?

2.15 Do you have a best friend?

2.16 How do you know this person? How long have known him/her?

2.17 How often do you see each other? What do you do together?

2.18 What clubs, teams, organizations or other groups in your school, church or in the community do you belong to?

2.19 I am especially interested in knowing how you deal with things that may be difficult in your family. Would you say that you can talk about things that are bothering you with other people in the family ....

all the time	_____1
most of the time	_____2
sometimes	_____3
never	_____4

2.20 Who do you now talk to most often about things going on in your family?

2.21 Has this changed in the last six months, (since _____ became ill? How?

2.22 Do you think people in your family can tell when something is bothering you.....

all of the time	_____1
most of the time	_____2
sometimes	_____3
never	_____4

2.23 When you are feeling sad?

all the time	_____1
most of the time	_____2
sometimes	_____3
never	_____4

2.24 When you are feeling angry?

all the time	_____1
most of the time	_____2
sometimes	_____3
never	_____4

People express their feelings differently and do different things to make them feel better when they're tense or upset. Some people like to exercise really hard. Others like writing, listening to music or hanging out with friends. Other people your age have told us that sometimes they feel so hurt and angry about their difficulties at home or at school that they strike out at whatever or whoever is around them.

2.25 What things do you do when you're tense or feeling down? When you're angry?

2.26 Now, I would like to ask you some questions about specific things you may do when you're tense or feeling down.

		N	R	S	O
A.	Do you read.....	0	1	2	3
B.	Do you listen to music.....	0	1	2	3
C.	Do you eat more food than usual.....	0	1	2	3
D.	Do you try to stay away from home as much as possible.....	0	1	2	3
E.	Do you do more at school.....	0	1	2	3
F.	Do you cry.....	0	1	2	3
G.	Do you watch T.V.....	0	1	2	3
H.	Do you write down how you feel.....	0	1	2	3
I.	Do you sleep more than usual.....	0	1	2	3
J.	Do you exercise.....	0	1	2	3
K.	Do you talk to a family member about what bothers you.....	0	1	2	3
L.	Do you spend more time alone.....	0	1	2	3
M.	Do you pray or go to church.....	0	1	2	3
N.	Do you smoke cigarettes.....	0	1	2	3
O.	Do you talk to a teacher or counselor at school about what's bothering you.....	0	1	2	3
P.	Do you spend time with friends.....	0	1	2	3
Q.	Do you drink beer, wine or liquor.....	0	1	2	3
R.	Do you use drugs not prescribed by a doctor.....	0	1	2	3
S.	Do you try to think of the good things in life.....	0	1	2	3
T.	Do you try to hurt someone or damage something.....	0	1	2	3
U.	Do you get angry and yell at people.....	0	1	2	3
V.	Do you try to figure out how to deal with your problems on your own.....	0	1	2	3
W.	Are there other things that you do when you are feeling down.....	0	1	2	3

(IF ANSWER TO W IS NEVER OR RARELY, SKIP NEXT QUESTION)

X. If "sometimes" or "often": What other things do you do when you're feeling down?

2.27 I am also interested in how you are doing in school right now. Did you miss any school in the last two months?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 2.28) (IF "NO", GO TO QUESTION 2.30)

2.28 If "yes": How many days?

_____ days

2.29 Why did you miss school in the last two months?

2.30 Approximately how many days per week did you miss school six months ago, before _____ became sick?

2.31 What kinds of grades did you get six months ago, before _____ was sick?

mostly As and Bs _____1
mostly Bs and Cs _____2
mostly Cs;some Ds _____3
mostly Ds and Fs _____4

2.32 What kind of school program are you in? (name, if possible)

Jr. High School.....1
General High School.....2
Academic or college prep.....3
Vocational School.....4
Commercial or Business.....5
Remedial or basic skills.....6
Special education.....7

2.33 What kinds of grades do you get?

mostly As and Bs _____1
mostly Bs and Cs _____2
mostly Cs;some Ds _____3
mostly Ds and Fs _____4

2.34 On most school days, how much time do you spend doing homework outside of school?

2.35 Are you satisfied with your school performance?

no.....0
yes.....1

If "no": How would you like it to be different?

How do you think you might accomplish this?

2.36 Do you currently have after school help with homework or tutoring?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 2.37) (IF "NO", GO TO QUESTION 2.38)

2.37 If "yes":

A. Where?

B. How often?

C. For how long?

D. Has it helped you improve your school work?

E. Why or why not?

(GO TO QUESTION 2.41)

2.38 If "no": Would it help you to have extra help with your school work now?

no.....0
yes.....1

If "yes": What kind of help? Where? How often?

2.39 Did you have after school help or tutoring in the past?

no.....0
yes.....1

2.40 If "yes":

A. Where?

B. How often?

C. For how long?

D. Did it help you improve your school work?

E. Why or why not?

F. Why did you stop having tutoring?

2.41 How far in school do you want to go?

2.42 What do you want to be when you grow up? What kind of a job do you want to have?

2.43 Have your plans for the future changed in the last six months, since _____'s illness?

At some point in their lives many children and teenagers feel they need to talk to someone outside of the family about things that are bothering them.

2.44 Who do you talk to about family problems?

(Interviewer: if child does not mention a professional ask question below. If child mentions professional, score yes below and ask if any other professional consulted)

Did you ever talk to anyone outside of your family and friends about family problems, emotional problems, behavior problems or problems with drugs or alcohol? That person might have been a guidance counselor at school, a priest, a social worker...

no.....0
yes.....1

(IF "YES", GO TO QUESTION 2.45) (IF "NO", GO TO QUESTION 2.52)

2.45 If "yes": Who did you talk to? Where was their office?

2.46 How often did you go? How did you get to the office?

2.47 For how long did you go?

2.48 Did you go alone?

no.....0
yes.....1

If "no": Who went with you?

2.49 How satisfied were you with the services you received? Would you say you were.....

very satisfied _____1
fairly satisfied _____2
fairly dissatisfied _____3
very dissatisfied _____4

2.50 Are you going to individual counseling now?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 2.58) (IF "NO", GO TO QUESTION 2.51)

2.51 Why did you stop going to counseling?

2.52 Do you think counseling would be helpful to you now?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 2.54) (IF "NO", GO TO QUESTION 2.53)

2.53 If "no": Why not?

(SKIP QUESTIONS 2.54-2.57) (GO TO QUESTION 2.58)

2.53 If "no": Why not?

(SKIP QUESTIONS 2.54-2.57) (GO TO QUESTION 2.58)

2.54 If "yes": Would you have a preference for a male or female counselor?

no preference/ male/ female

2.55 How often would you want to see a counselor?

2.56 Where would you prefer to see the counselor?

no preference/office/ in home/ other

2.57 What has prevented you from seeing a counselor until now?

2.58 Have you ever been to any kind of group counseling session?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 2.59) (IF "NO", GO TO QUESTION 2.66)

2.59 For how long?

2.60 How often?

2.61 Where do you meet?

2.62 Who else is in the group?

2.63 Do you feel that being in a group like this is helpful?

no.....0
yes.....1

If "yes": Why?

2.64 How satisfied were you with the services you received? Would you say you were.....

very satisfied _____1
fairly satisfied _____2
fairly dissatisfied _____3
very dissatisfied _____4

2.65 Would you recommend being in a group to other young people who have been through the kinds of difficulties you have been through?

no.....0
yes.....1

Why? or Why not?

(SKIP QUESTIONS 2.66-2.68)(GO TO QUESTION 2.69)

2.66 If "no": Would you ever consider being in a group?

no.....0
yes.....1

(IF "NO", GO TO QUESTION 2.67) (IF "YES", GO TO QUESTION 2.68)

2.67 If "no": Why not?

2.68 If "yes": What has prevented you from being in a group?

2.69 During the past year, were you able to get all the kinds of help you wanted, when you needed it?

no.....0
yes.....1

2.70 Please tell me if you needed or wanted any of the following services in the past year, and if you did want them, were you able to get them.

		Wanted Service		Received Service	
		YES	**NO**	**YES**	**NO**
A.	medicine to help you with a problem for the way you were feeling or acting.....	Y	N	Y	N
	If received, from who?				
B.	help with a health problem, like an illness or injury....	Y	N	Y	N
	If received, from who?				
C.	counseling or treatment for a drug or alcohol problem.....	Y	N	Y	N
	If received, from who?				
D.	help dealing with the police or juvenile justice system...	Y	N	Y	N
	If received, from who?				
E.	help with sports or other after school activities.....	Y	N	Y	N
	If received, from who?				
F.	help working things out with your parents/guardian.....	Y	N	Y	N
	If received, from who?				

G. help with making friends
or getting along with others. Y N Y N

If received, from who?

(IF SERVICE DESIRED, BUT NOT RECEIVED, GO TO QUESTION 2.71)

(IF ALL SERVICES DESIRED WERE RECEIVED, GO TO QUESTION 2.72)

2.71 Lots of different things can prevent someone from getting help or can make it difficult to do so. What prevented you from getting the help you wanted?

2.72 We are doing this project in order to know from young people like you what you would recommend to others who are going through similar experiences.

What kinds of advice would you give someone going through the same kinds of things you have been experiencing?

2.73 We have thought of a number of different services that might be appropriate for young people like you. Would you recommend....

		YES	NO
A.	individual counseling	Y	N
B.	group counseling	Y	N
C.	peer counseling	Y	N
D.	recreational programs		
DA.	arts	Y	N
DB.	sports	Y	N

2.74 What would help you most right now?

2.75 Are there other things you haven't told me about the changes you have been going through?

2.76 What is the best thing that you have done for yourself in the last year? Why was it the best thing?

2.77 If you could have three wishes for anything you wanted, what would they be?

2.78 If you could be any kind of animal you wanted to be, what would choose? Why would you want to be a _____?

Introduction to Achenbach Scale

I enjoyed talking with _____. I would like to ask you some questions about him/her. This will give me an idea of how you think _____ is doing. It will also give me an idea of what kinds of services would help you and your family right now.

****

Follow-Up with Parent after the Achenbach Scale.

3.1 What concerns you most about _____ right now?

3.2 Do you see the current living arrangement as permanent? Do you expect to have _____ living with you until she/he is old enough to be living on his/her own.

no.....0
yes.....1

3.3 Though many parents don't make arrangements for who they would want their children to live with if they died it is recommended that they do so. Have you thought about or made arrangements for who you would want to be _____'s guardian if you should die?

no.....0
yes.....1

(IF YES, GO TO QUESTION 3.4. IF NO, GO TO QUESTION 3.7)

3.4 If "yes", who would you want your children to live with if you died?

3.5 Have you spoken with (the proposed guardian) about that? How do they feel about it?

3.6 Have you spoken with the children about it?

3.7 If "no", is this a topic that your caseworker has brought up?

no.....0
yes.....1

(IF NO, GO TO QUESTION 3.8. IF YES, GO TO QUESTION 3.9)

3.8 If "no", is this something that you would like to talk with your caseworker or someone else about?

(SKIP NEXT QUESTION)

3.9 If, "yes", what did your caseworker talk to you about in relation to custody issues?

3.10 What has been the most stressful thing about having _____ in your home since you became ill?

3.11 Do you get enough time alone or enough time to spend with your children?

no.....0
yes.....1

If "no": How much time would you like to have alone or to spend with family?

3.12 Who takes care of _____ if you need to keep an appointment or you want to go out without him/her?

3.13 Do you ever have to make special child care arrangements for _____ that last overnight or longer?

no.....0
yes.....1

If "yes": What kinds of arrangements do you make?

3.14 How much support do you get for being a parent from your family and friends?

3.15 Who do you talk to about problems or things that trouble you about _____?

3.16 How well do you feel _____ has adjusted to the changes in his/her life since _____ you became ill?

3.17 How would you say _____ has been emotionally since your illness?

Have you been able to speak to _____ about your illness?

no.....0
yes.....1

If "no", do you plan to tell _____ that you have AIDS?

no.....0
yes.....1

Why or Why Not?

What do you think would help you most in talking to _____ about your illness?

If "yes", what was _____ reaction to your speaking to him/her about your illness?

How do you think _____ is handling the information and their feelings about your illness?

At some point in their lives many people feel they need to talk to someone outside of the family about things that are bothering them.

3.18 You have been through a very stressful time. We would like to know about what kinds of things you have been able to do for yourself to help you get through this time.

Did you ever talk to anyone outside of your family and friends about family problems, emotional problems, behavior problems or problems with drugs or alcohol? That person might have been a guidance counselor at school, a priest, a social worker..

no.....0
yes.....1

(IF "YES", GO TO QUESTION 3.19) (IF "NO", GO TO QUESTION 3.26)

3.19 If "yes": Who did you talk to? Where was their office?

3.20 How often did you go?

3.21 For how long did you go?

3.22 Did you go alone?

no.....0
yes.....1

If "no": Who went with you?

3.23 How satisfied were you with the services you received?
Would you say you were.....

very satisfied _____1
fairly satisfied _____2
fairly dissatisfied _____3
very dissatisfied _____4

3.24 Are you receiving these services now?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 3.32) (IF "NO", GO TO QUESTION 3.25)

3.25 Why did you stop going to counseling?

3.26 Do you think individual counseling would be helpful to you now?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 3.28) (IF "NO", GO TO QUESTION 3.27)

3.27 If "no": Why not?

(SKIP QUESTIONS 3.28-3.31) (GO TO QUESTION 3.32)

3.28 If "yes":

Would you have a preference for a male or female counselor?

no preference/ male/ female

3.29 How often would you want to see a counselor?

3.30 Where would you prefer to see the counselor?

no preference/ office/ in home/ other

3.31 What has prevented you from seeing a counselor until now?

3.32 Have you ever been to any kind of group counseling session?

no.....0
yes.....1

(IF "YES", GO TO QUESTION 3.33) (IF "NO", GO TO QUESTION 3.40)

3.33 How long?

3.34 How often?

3.35 Where did you meet?

3.36 Who else was in the group?

3.37 Do you feel that being in a group like this is helpful?

no.....0
yes.....1

If "yes", how is it helpful?

3.38 How satisfied were you with the services you received? Would you say you were.....

very satisfied	_____1
fairly satisfied	_____2
fairly dissatisfied	_____3
very dissatisfied	_____4

3.39 Would you recommend being in a group to other people who have been through the kinds of difficulties you have been through?

no.....0
yes.....1

Why or why not?

(SKIP QUESTIONS 3.40-3.42)(GO TO QUESTION 3.43)

3.40 If "no": Would you ever consider being in a group?

(Interviewer, please ask if interested in group if others in group have families with similar experiences with illness, problems with children etc.)

no.....0
yes.....1

(IF "NO", GO TO QUESTION 3.41) (IF "YES", GO TO QUESTION 3.42)

3.41 If "no": Why aren't you interested in being in a group?

3.42 If "yes": What has prevented you from being in a group?

3.43 What clubs, organizations, church groups or other groups do you belong to? How often do you meet with them?

3.44 During the past year, were you able to get all the kinds of help you wanted, when you needed it?

no.....0
yes.....1

3.45 Please tell me if you needed or wanted any of the following services in the past year, and if you did want them, were you able to get them.

		Wanted Service YES	Wanted Service NO	Received Service YES	Received Service NO
A.	medicine to help you or someone in the family with a problem for the way they were feeling or acting	Y	N	Y	N
	If received, from who?				
B.	help with a health problem in family, like an illness or injury	Y	N	Y	N
	If received, from who?				
C.	counseling or treatment for a drug or alcohol problem of yours or of someone in the family	Y	N	Y	N
	If received, from who?				
D.	help dealing with the police or justice system	Y	N	Y	N
	If received, from who?				
E.	help with problems children in the family were having in school	Y	N	Y	N
	If received, from who?				
F.	baby sitting or child care	Y	N	Y	N
	If received, from who?				
G.	help coping with your grief and the children's grief	Y	N	Y	N
	If received, from who?				
H.	help understanding and applying for benefits for children	Y	N	Y	N
	If received, from whom?				
I	help finding a larger place to live	Y	N	Y	N
	If received, from whom				
J.	Other_____				

(IF SERVICE DESIRED, BUT NOT RECEIVED, GO TO QUESTION 3.46)
(IF ALL SERVICES DESIRED WERE RECEIVED, GO TO QUESTION 3.47)

3.46 Lots of different things can prevent someone from getting help or can make it difficult to do so. What prevented you from getting the help you wanted?

Are there things that you think we might be able to do for you that would help you and your children right now?

3.47 We are doing this project in order to know from people like you what you would recommend to others who are going through similar experiences. What kinds of advice would you give someone going through the same kinds of things you have experienced since you became ill?

3.48 We have thought of a number of different services that might be appropriate for people like you and your family. Would you recommend....

For the children:

		YES	NO
A.	individual counseling.....	Y	N
B.	group counseling.....	Y	N
C.	peer counseling.....	Y	N
D.	recreational programs		
	DA. arts.....	Y	N
	DB. sports.....	Y	N
E.	Other_____		

For you:

		YES	NO
A.	individual counseling.....	Y	N
B.	group counseling.....	Y	N
C.	parenting classes.....	Y	N
D.	parent support group.....	Y	N
E.	adult education classes.....	Y	N
F.	senior citizens group.....	Y	N
G.	Other_____		

3.50 What would help you most right now?

3.51 What is the best thing you have done for yourself in the last year? Why was it the best thing?

3.52 Is there anything else that you would like to talk about before we complete the interview?

****

Lastly:

We will now give you a questionnaire which is totally private and which you can give back to us in the blank envelope. Please do not put your name on it anywhere. It asks private questions. Once we have collected all these questionnaires, we will look at them. We will not be able to trace which persons answered them. That way, they will be totally private.

YOUTH PROJECT
SELF-REPORT QUESTIONNAIRE

INSTRUCTIONS: **DO NOT PUT YOUR NAME ON THIS FORM.**

PLEASE PUT YOUR AGE AND SEX BELOW AND CIRCLE WHICH ETHNIC GROUP YOU IDENTIFY YOURSELF WITH MOST STRONGLY.

PLEASE REMEMBER THAT I WILL NOT TALK ABOUT YOUR ANSWERS TO THESE QUESTIONS WITH YOUR PARENTS, TEACHERS OR ANYONE ELSE.

PLEASE ANSWER ALL OF THE QUESTIONS BY PUTTING A CIRCLE AROUND THE ANSWER YOU CHOOSE.

THANK YOU!

AGE:_____ SEX:_____ ETHNICITY:_____

Where was your mother born?

Where was your father born?

Where were you born?

What group do you identify with most strongly? Please circle below or write in if your group is not listed.

Black

Black American
Black Caribbean
Black African
Black Other

White

Native American

Hispanic

Puerto Rican
Dominican
Cuban
Mexican
Hispanic Other

Mixed

Asian and Black
Asian and Hispanic
Asian and White
Black and White
Black and Hispanic
Hispanic and White

Asian

Asian Middle Eastern
Asian Oriental
Asian Indian

Other (Please write)

4.1 Have you done any of the following with a boyfriend or girlfriend? (you can choose more than one answer)

	YES	NO
Kissing	Y	N
Hugging	Y	N
Masturbation	Y	N
Touching	Y	N
Rubbing Bodies	Y	N

4.2 A. Have you ever been involved with someone sexually where you had vaginal (penis in the vagina), oral (penis to mouth or mouth to vagina) or anal intercourse (penis in the anus)?

no.....0
yes.....1

B. Have you ever been forced to have sexual intercourse with someone you did not want to?

no.....0
yes.....1

C. Have you ever had intercourse for money, drugs, food or a place to sleep/live?

no.....0
yes.....1

If you answered "no" to A, B, and C please go on to question 4.3.

If you answered "yes" to A, B, or C, please answer all the questions below

Were the people you had sexual intercourse with.....

Boys (men).....0

Girls (women).....1

Both boys (men) and girls (women).....2

How old was the first and last person you had intercourse with?

4.3 (For girls) Have you ever been pregnant?

no.....0
yes.....1

(For boys) Have you ever made a girl pregnant or been a father?

no.....0
yes.....1

4.4 Have you ever had a sexually transmitted disease (also called VD), like Chlamydia, gonorrhea (clap), syphilis, or trichomonas.

no.....0
yes.....1

4.5 Did anyone ever explain to you or have you seen or heard information on how you can protect yourself from getting a sexually transmitted disease?

no.....0
yes.....1

If "yes", how did you learn about how you can protect yourself against getting a sexually transmitted disease?

4.6 What can you do to protect yourself against VD?

wash yourself after having sex.....1
use a condom.....2
use birth control pills.....3
look to see if your partner has VD.....4

4.7 A condom should never be used more than one time.

True False

4.8 Having only one sexual partner protects you from getting a sexually transmitted disease.

True False

4.9 Do you or members of your family or close friends ever use any of the following:

Substance	**Do you ever use**		**Do members of your family or close friends use**	
A.Cigarettes	Yes	No	Yes	No
B.Beer	Yes	No	Yes	No
C.Wine	Yes	No	Yes	No
D.Liquor	Yes	No	Yes	No
E.Amphetamines (uppers, speed)	Yes	No	Yes	No
F.Barbiturates (downers, bennies)	Yes	No	Yes	No
G.Tranquilizers (valium, Xanex)	Yes	No	Yes	No
H.Marijuana	Yes	No	Yes	No
I.Cocaine (nose)	Yes	No	Yes	No
J.Cocaine (needle)	Yes	No	Yes	No
K.Crack	Yes	No	Yes	No
L.Heroin (nose)	Yes	No	Yes	No

M.Heroin (needle)	Yes	No	Yes	No
N.Speedball	Yes	No	Yes	No
O.Ecstasy	Yes	No	Yes	No
P.Ice	Yes	No	Yes	No
Q.Psychedelics (LSD, Mescaline)	Yes	No	Yes	No

4.8 Below, please write down the substances which you use now and how many times in the last month you have used them.

Substance you use now	**Number of times in last month**
1.	
2.	
3.	
4.	
5.	
6.	
7.	

WHEN YOU ARE DONE WITH THESE QUESTIONS, PLEASE PUT THEM IN THE ENVELOPE AND GIVE THE ENVELOPE TO THE PERSON WHO IS INTERVIEWING YOUR FAMILY.

IF YOU WANT TO TALK TO SOMEONE ABOUT ANY OF THESE QUESTIONS AND YOUR ANSWERS TO THEM, PLEASE CALL JOSE SEGURA OR JAN HUDIS AT (212) 966-8112. THEIR TELEPHONE NUMBER IS ON THE CARD. PLEASE TAKE THE CARD AND USE THE NUMBER TO GET IN TOUCH WITH THEM. THERE IS AN ANSWERING MACHINE ON THE PHONE. IF NO ONE IS THERE TO ANSWER YOUR CALL IN PERSON, PLEASE LEAVE YOUR NAME AND NUMBER AND JAN OR JOSE WILL CALL YOU BACK. IF THERE IS A PROBLEM WITH US REACHING YOU BY PHONE PLEASE LET US KNOW WHEN YOU WILL BE ABLE TO CALL AGAIN OR SOME OTHER WAY WE CAN GET IN TOUCH WITH YOU.

THANK YOU FOR HELPING US WITH THIS INFORMATION.

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