The Personnel Needs Study Part II:
Delivering HIV/AIDS Care:
The Professional Care Provider Speaks Out

Columbia School of Public Health

This study is supported under contract # 93 EVL-4645A from the Medical and Health Research Association of New York City, Inc. (MHRA), with funds from the Health Resources and Services Administration (HRSA) under the Ryan White CARE Act Title I.
THE PERSONNEL NEEDS STUDY PART II:
DELIVERING HIV/AIDS CARE:
THE PROFESSIONAL CARE PROVIDER SPEAKS OUT

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ACKNOWLEDGMENTS

The authors wish to extend their sincere thanks to the many persons who gave of their time to participate in the personal interviews that form the basis for this report. This report would not be possible without the health and social service providers who work hard to provide compassionate and technically superior care to the HIV positive community in New York City. We are extremely grateful that the 86 providers interviewed took time away from the hectic professional schedules to speak with us and to share their personal experiences.

We have greatly benefited from our ongoing collaboration with our primary technical officers on this project. Dorothy Jones-J Jessup, Ph.D., Kathy Nelson, Ph.D., and Kimberly Fox from the Medical and Health Research Association of New York City, Inc and Deisha Letter from New York City Department of Health have always been there to guide the development and execution of our evaluation studies. We have also benefited from their careful review and comments on this and other project reports. We also wish to thank the Council’s Planning and Evaluation Committee, and in particular the valuable insights of David Hensel, J.D., past chair, and Elizabeth Vega Lobo, the current chair. We also wish to express our appreciation for the unfailing work of our staff. Helena-Maria Lekas provided invaluable assistance in the qualitative data analysis. We would especially like to thank Bernadette Brusco for her persistence and powers of persuasion in organizing, the interview schedules among 29 agencies and 6 interviewers.
• Organizational issues including poor supervision, lack of institutional support, and low salaries add to stresses on health care and social service providers.

• Providers reported a fear of TB infection more frequently than fear of HIV infection.

• Providers reported that client deaths, youth of the clients and the unpredictable decline of their patients were among the most stressful aspects of working in HIV/AIDS services.

• Issues around confidentiality including disclosure of HIV status to partners, family members and other health care providers add to the stress of work for health care and social service providers.

• Providers feel that the social stigma of HIV/AIDS is a factor in the mental health and well-being of clients, and report a sense of frustration in coping with patient denial and depression.

• Staff reported that training and education on grief, bereavement and coping with terminal illness would help support their work in HIV/AIDS services.

• All health professional groups underscored the need for training to keep them up-to-date on HIV/AIDS clinical care and to learn about emerging prevention strategies.
INTRODUCTION

The Ryan White Title I Evaluation Personnel Needs Study Part II: Delivering HIV/AIDS Services: The Professional Provider Speaks Out reports on a series of open-ended interviews exploring the unique stresses faced by health care and social service providers working within the HIV/AIDS epidemic. The interviews with agency staff are a follow up to a previous study of the Personnel Needs of HIV/AIDS service agencies in New York City (Technical Report #2). The interviews were designed to permit nurses, doctors and social service providers (i.e. MSWs, case managers, counselors and health educators) to tell their stories of working within the HIV/AIDS epidemic in New York City and to provide guidance to development of institutional supports which would help them to continue providing quality medical and social services to their clients.
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EXECUTIVE SUMMARY

The Ryan White Title I Evaluation Personnel Needs Study Part II: Delivering HIV/AIDS Services: The Professional Care Provider Speaks Out is a study of the unique stresses and satisfactions experienced by health care and social service providers working in HIV/AIDS service agencies in New York City. The study is based on open-ended personal interviews with 86 randomly sampled providers from 29 randomly sampled HIV/AIDS service agencies. The interviewed staff told us in their own words the frustrations and personal fulfillment they experienced in working with HIV positive clients. Those interviewed also completed the Maslach Burnout Inventory (MBI), a commercially developed burnout scale, to facilitate a more structured comparison of their feelings of burnout against national norms.

Interview transcripts were analyzed for content focusing on three broad themes: what is uniquely stressful about working in HIV/AIDS services, what are the positive aspects of working in HIV/AIDS services, and what institutional supports can be put in place to support providers and to maintain high quality of HIV/AIDS care. The report summarizes the results of the content analysis of the interview transcripts and provides a brief analysis of the MBI scores.

Although health care and social service providers discussed a number of generic stresses related to the health care environment, the interviews provide a strong sense of the unique...
issues confronted by those working in the HIV/AIDS epidemic. Providers felt strongly about their clients' well-being and most expressed a deep personal commitment to the epidemic. Many described working vigorously for the clients against the "AIDS system" to obtain needed services and entitlements. Providers stressed that HIV-positive clients had complicated needs that went beyond those related to the illness. Most providers felt that their work made a difference in clients' lives and valued the relationships they developed with them. Many providers regarded the intimacy of their relationship with their clients as the most positive aspect of working with HIV-positive patients.

Using the MBI, those interviewed were measured for burnout in three domains: emotional exhaustion, depersonalization, and personal accomplishment. Surprisingly, interviewees in general are not experiencing feelings of burnout at higher levels than those found in national comparative surveys of professionals. Compared to the national norm, the randomly selected sample of health care and social service providers showed average levels of personal accomplishment and below average levels of depersonalization, and average levels of emotional exhaustion. These findings may indicate that the MBI is not sensitive to the complex social situation surrounding HIV/AIDS services. The results of the in-depth interviews suggest that the level of personal choice involved in working in HIV/AIDS care may bias results on the MBI toward the mean. The in-depth staff interviews confirm that HIV/AIDS care providers feel a high level of personal commitment to working with HIV-positive clients.
This personal commitment to improving the lives of their HIV positive clients may blunt some of the more stressful aspects of working in HIV/AIDS services.

Key Findings:

- Health care and social service providers across professional category reported a sense of personal connection to their clients.

- Providers who were able to view patient progress in small increments reported a high level of personal satisfaction from client-provider interactions.

- Interviewees in general scored within the national average on the MBI subscale for emotional exhaustion.

- Interviewees scored higher than the national average on the MBI subscale for personal accomplishment, perhaps signaling an ability to measure progress for HIV positive clients in small steps.

- Interviewees scored lower than the national norm for the MBI depersonalization subscale (i.e., they are less depersonalized).

- Having a formal or an informal support system helps providers across category cope with HIV-related stress issues.

- Many providers suggested that peer support across institutions was helpful, and many providers have informally organized networks of peers to support them in their work.

- Working as part of a team, either multi-disciplinary or homogeneous helps providers diffuse the stress of working with complex and demanding client caseloads.

- Personal support systems including supportive co-workers, families or partners were viewed as critical to the continued ability of providers working in HIV/AIDS services.
BACKGROUND

As the HIV/AIDS epidemic moves into its second decade, the human and social costs of treating and caring for an expanding population of HIV positive patients have created difficult choices regarding the organization, distribution and support of medical and social services. New York City has provided a wide spectrum of services to the HIV positive community in New York, and there has been a concomitant investment of human capital on the part of health and social service providers. These staff interviews document some of the unique experiences and coping systems developed by providers working in HIV/AIDS in New York City.

The interviews described here suggest that the HIV/AIDS epidemic has raised a variety of potentially stressful issues for health care and social service providers. Potential stressors include the social stigma of HIV, the unpredictability of the progress of HIV/AIDS and the few medical interventions of demonstrated efficacy. Although overall incidence of HIV/AIDS may be decreasing, aggressive efforts to identify HIV positive individuals at an earlier stage of the disease may well lead to increased strains on the health care and social service delivery mechanisms developed to meet current demand. In New York City, as elsewhere, health care and social service providers who work with HIV positive patients increasingly face a continuous demand for services while battling decreasing patient entitlements and decreasing operating budgets; a situation bound to produce feelings of frustration, anger and despair in providers of crucial services.
The emotional and psychological impact of working within the HIV/AIDS epidemic has prompted many to hypothesize that human service providers working with HIV positive individuals may be especially vulnerable to burnout. This study explores this possibility of burnout with 86 randomly selected health and social service providers through open-ended interviews and a commercially developed survey administered burnout inventory.

The staff interviews highlight key issues for health care and social service providers working in HIV/AIDS as they attempt to fulfill multiple service roles. The Maslach Burnout inventory was administered to all interviewees to explore the level of burnout among HIV/AIDS service providers in contrast to others working in health care and social service fields.

METHODOLOGY

Sample Selection

Respondents in the staff survey were providers of health and human services for HIV positive individuals who worked in a subset of the 92 agencies that participated in the first phase of the Ryan White Care Act Personnel Needs Study. All agencies participating in the first phase of this study were eligible to serve as sites for staff interviews. Forty agencies were randomly sampled for the staff interview phase of the study and interviews were ultimately...
conducted at 29 agencies. The 29 participating agencies were representative of the larger parent sample. Agencies ranged from hospital-based units to outreach and education programs to HIV/AIDS-designated dental clinics.

As part of the earlier Personnel Needs survey, participating agencies had enumerated all staff positions providing specialized HIV/AIDS services. These staff enumerations provided a complete list of job titles and the initials of current occupants of each position. Staff positions were then grouped into seven broad job categories: nurses, MDs, education & community outreach, case management staff, other health care professionals, administrative positions and all other job titles. From each agency we drew two to four names. Names were sampled within selected job categories in each agency to yield a balanced number of interviews with staff from each of the above job categories.

To recruit respondents, letters were sent to agency contacts describing the second phase of the study with a list of selected respondents by position and initials at their agency. Agency contacts approached the sampled staff to obtain agreement to be contacted about the study. Staff agreeing to be contacted were then telephoned by the Columbia evaluation team who described the staffing study in more detail and attempted to schedule the interview. Columbia obtained upon request from the authors.

Of all staff contacted only one person refused to be interviewed and one agency refused to allow any staff to participate in the staff interviews.
staff explained that the interview would explore the individual experiences of the respondent and that the interview was an opportunity for them to tell us first hand what it was like to work in the HIV/AIDS epidemic. This report provides a summary of the experiences of a sample of health care and social service providers working in HIV/AIDS care in New York City.

Columbia staff stressed that the interview was not an evaluation of the agency or of the individual, but rather an opportunity for the staff person to make concrete suggestions about how to better support providers of health care and social services to the HIV positive community in New York City. Respondents were given an information sheet with assurances that the contents of the interview would be kept strictly confidential. Among the 90 staff sampled in this way, interviews were completed with 86, yielding a 96% response rate.

Development of the Interview Guide

A semi-structured interview guide was developed based upon a focus group with professionals who have extensive experience working with persons with HIV/AIDS. Input for the interview guide was also solicited from the New York Academy of Medicine, the New York City Department of Health, the Medical Health Research Association of New York City, Inc. and prominent social service researchers working with medical care providers in the HIV/AIDS field. The guide is a series of open-ended questions intended to stimulate a discussion about the respondents own work experiences. Questions center around three major
areas: what is stressful about working in HIV/AIDS services, what is personally satisfying about the work, and what institutional support would help make their job easier. Appendix A presents a copy of the interview guide.

Interviews were conducted by a trained group of interviewers, several of whom were faculty of the Columbia School of Public Health. All interviews were completed on site at the agency in private offices to facilitate a sense of privacy during the interviews. Agency contacts cooperated in facilitating the use of such spaces when respondents did not have offices. All respondents agreed to audio-taping of their interviews. The interviews were transcribed, deleting references to names and any other personal identifiers. The transcribed interviews exceeded 2000 pages of transcript. Inaudible portions resulted in partial transcriptions for 16 of the 86 interviews.

Maslach Burnout Inventory

In addition to the semi-structured interviews, all respondents were asked to complete the Maslach Burnout Inventory (MBI). This proprietary inventory of 22 questions across three domains permitted examination of whether HIV/AIDS service providers in New York City were more or less "burnt out" than human service professionals surveyed across the United States. The MBI has been administered and validated for a variety of service providers over the
course of 10 years. Ranges for general populations of health care and social service providers
have been developed based upon this work. The MBI also includes a demographic form on
which individuals self-identified their primary work area, job title and organizational position
into preceding categories. A copy of the MBI appears in Appendix B.

There was some concern that responses to the MBI might be affected if it was completed
exclusively at the start or at the conclusion of the interview. We therefore randomly
administered the MSI before or after the interview. The results of this variation indicated that
responses were not affected by the sequencing of interview and MBI. There were no
statistically significant differences in mean values between MBI scales completed before versus
after the interview.

DEMOGRAPHIC AND JOB CHARACTERISTICS OF SAMPLE

Table 1 summarizes demographic information collected during each interview. Most
respondents were under the age of 40, two-thirds were women and slightly more than 40
percent were married. The sample was ethnically and racially diverse. Although non-Latino
whites was the largest racial group (37 percent), interviews were also conducted with
substantial numbers of African Americans (27 percent) and staff of Hispanic origin (28
percent). The respondents generally had completed some amount of college and more than half
of the sample had a graduate degree.
Table 1 summarizes the type of work performed by the sample. Most fall into one of three primary work areas. Over a third work in medical care, 22 percent are in social services and 21 percent provide counseling services. Respondents occupy a large number of job titles.
with the most frequent being case managers, nurses, outreach workers, MDs and administrative positions. Approximately one half of the respondents have been working in their current line of work for 5 or more years. More than a quarter of the respondents have been in the same area of work for ten or more years; only 15 percent of respondents had been working in their field for less than two years. By contrast, most respondents have been working in their current job for a relatively short period of time. Half the respondents have been working in their current job for less than two years and only 22 percent have been working in the same position for more than five.
### Table 2 - Job Characteristics of Sample Health Professionals (N=86)

<table>
<thead>
<tr>
<th>Primary Work Area</th>
<th>Percent of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td>37%</td>
</tr>
<tr>
<td>Mental Health</td>
<td>9%</td>
</tr>
<tr>
<td>Social Services</td>
<td>22%</td>
</tr>
<tr>
<td>Counseling</td>
<td>21%</td>
</tr>
<tr>
<td>Other</td>
<td>11%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Professional Title</th>
<th>Percent of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrative</td>
<td>12%</td>
</tr>
<tr>
<td>Case Management</td>
<td>16%</td>
</tr>
<tr>
<td>Mental Health Counselors</td>
<td>8%</td>
</tr>
<tr>
<td>Outreach</td>
<td>13%</td>
</tr>
<tr>
<td>Nursing</td>
<td>14%</td>
</tr>
<tr>
<td>MDs (includes 1 PA)</td>
<td>12%</td>
</tr>
<tr>
<td>Social Workers</td>
<td>6%</td>
</tr>
<tr>
<td>Substance Abuse</td>
<td>2%</td>
</tr>
<tr>
<td>Other medical position</td>
<td>8%</td>
</tr>
<tr>
<td>Dentists</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years in Type of Work</th>
<th>Percent of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year or less</td>
<td>8%</td>
</tr>
<tr>
<td>More than 1 year, less than 2 years</td>
<td>7%</td>
</tr>
<tr>
<td>2 years, less than 5 years</td>
<td>30%</td>
</tr>
<tr>
<td>5 years, less than 10</td>
<td>23%</td>
</tr>
<tr>
<td>10 or more years</td>
<td>28%</td>
</tr>
<tr>
<td>Missing</td>
<td>4%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years in Current Job</th>
<th>Percent of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year or less</td>
<td>31%</td>
</tr>
<tr>
<td>More than 1 year, less than 2 years</td>
<td>20%</td>
</tr>
<tr>
<td>More than 2 years, less than 5 years</td>
<td>24%</td>
</tr>
<tr>
<td>More than 5 years, less than 10 years</td>
<td>22%</td>
</tr>
<tr>
<td>Missing</td>
<td>3%</td>
</tr>
</tbody>
</table>

**BURNOUT AS A FUNCTION OF HIV/AIDS CARE**

Although many of the stresses that health care and social service providers working
with HIV/AIDS face are common to all health care settings, it has been suggested that there are some "uniquely stressful" aspects of working with HIV and AIDS. The staff attempted to contrast the normal stresses of work in social and medical services with those "unique" stresses of working within the HIV/AIDS epidemic. Table 5 reproduced from Cooke contrasts generic stresses in health care with stressors associated with diseases with poor prognosis and stressors typical of HIV/AIDS. Interviews suggested that institutional variables including low pay, small office space, high caseloads, poor geographic location, poor supervision or lack of supervision contribute to stress levels of the health care and social service providers. However, some of these stresses are more generic and not specific to the HIV/AIDS care environment.
The staff interviews were specifically focused on eliciting information that would help insure a continuous level of high quality patient care to the HIV positive community in New York City by exploring which issues contribute to unnecessary stress and burnout among service providers. The term ‘burnout’ was for this survey used to describe symptoms experienced by providers in heavy client contact. Burnout encompasses everything from a mild malaise and dragging feeling about work to overwhelming despair. In the context of
This survey was concerned with burnout on the individual level as well as on the institutional or agency level. Burnout on either level has potentially critical implications for HIV/AIDS services, especially if burnout is reflected in a diminished quality of care for clients. Burnout can lead to distance between providers and clients and potentially the development of negative and cynical attitudes about clients. Staff experiencing burnout may arrive late and leave early, postpone work, fail to concentrate on clients and avoid direct client contact. Negative attitudes toward clients can influence interactions between providers and clients, and may lead to poor treatment and inadequate services. Provider burnout can be linked to both a decreased quality of care and low staff morale. Since factors which produce stress can be personal, organizational or contextual, the staff interviews attempted to identify aspects of HIV/AIDS care specifically which may be correlated with stress induction.

Measuring Burnout

The Maslach Burnout Inventory administered to all who provided interviews is the most widely accepted measure of burnout. The MBI was developed to quantify aspects of the burnout syndrome. The MBI has three subscales that measure emotional exhaustion, depersonalization and lack of personal accomplishment. The three subscales are considered
highly reliable as measures of feelings of being overwhelmed by work; impersonal responses to clients; and feelings of competence and achievement. Burnout is measured on a continuum from low to moderate to high.

The inventory attempts to measure feelings of being mentally exhausted through 22 statements which measure feelings toward the work environment, colleagues, clients and one's personal goals. The MBI asks respondents to say how often they experience these feelings on a seven degree Likert type scale with increments ranging from "never" to "every day."

Respondents received a score for each subscale.

The MBI considers the three subscales highly correlated, but does not use an additive measure to produce a final measure of burnout. However, the MBI does relate scores on the subscales to one another. Respondents who score high in both Emotional Exhaustion and Depersonalization and low in the Personal Accomplishment subscale are considered to have a very high degree of burnout. Respondents who have average scores on all three subscales are considered as having an average level of burnout. Respondents who score high in Personal Accomplishment and low in Emotional Exhaustion and Depersonalization are considered to have a low degree of burnout.

Test of the subscales' internal consistencies in this sample (N=86) showed that the
emotional exhaustion subscale to be highly reliable (Cronbach's alpha = .87), while the
depersonalization subscale (Cronbach's alpha = .64) and personal accomplishment (Cronbach's
alpha = .48) were moderately reliable. The reliability for emotional exhaustion was similar to
that reported by Maslach and Jackson for the national sample (Cronbach's alpha = .90).

Reliability coefficients for the depersonalization and personal accomplishment subscales were
also smaller in the Maslach and Jackson national sample, although the decline was not as great
as in the staffing sample (the respective Cronbach's alphas in the national sample were .79 and
.71).

The emotional exhaustion and depersonalization subscales were moderately correlated (r
= .46). The personal accomplishment subscale, as would be expected, was inversely related to
the other two subscales, although the correlation was low with both emotional exhaustion (r =-
.16) and depersonalization (r = -.24). The correlations between the subscales in the sample for
this study are similar to those reported by Maslach and Jackson.

RESULTS

Our analysis begins with a summary based upon staff answers to the Maslach Burnout
Inventory (MBI). We then draw upon the findings of the qualitative interviews to develop and
expand upon the quantitative findings of the MBI.
The Maslach Burnout Inventory

Table 4 presents mean values for each MBI subscale broken down by primary work area. The meaning of these findings can be best understood when presented in graphic form. Figure 1 plots the mean values. The horizontal lines on the graphs show for each scale the breaks between the lower, middle and upper third of scores from national samples serving as norms for the MBI. Maslach and Jackson interpret high scores to be those in the upper third of the normative distribution on emotional exhaustion, depersonalization and lower third on personal accomplishment. The filled in squares on the graphs present, as further points of references, mean values for national norms for medical, mental health and social service providers.
Figure 1 - Mean MBI Scores by Primary Work Area

**Personal Accomplishment Subscale**

Mean Scale Score

primary work area

**Emotional Exhaustion Subscale**

Mean Scale Score

primary work area

**Depersonalization Subscale**

Mean Scale Score

primary work area
<table>
<thead>
<tr>
<th>Primary Work Area</th>
<th>N</th>
<th>Mean Score Depersonalization Subscale</th>
<th>N</th>
<th>Mean Score Emotional Exhaustion Subscale</th>
<th>N</th>
<th>Mean Score Personal Accomplishment Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Population [National Norm]</td>
<td>79</td>
<td>4.9 (3.9)</td>
<td>84</td>
<td>19.9 (10.1)</td>
<td>79</td>
<td>39.8 (5.7)</td>
</tr>
<tr>
<td>Medical           [National Norm]</td>
<td>31</td>
<td>5.4 (4.3)</td>
<td>32</td>
<td>22.2 (10.7)</td>
<td>31</td>
<td>39.6 (6.0)</td>
</tr>
<tr>
<td>Mental Health     [National Norm]</td>
<td>8</td>
<td>6.0 (4.7)</td>
<td>8</td>
<td>22.0 (7.7)</td>
<td>8</td>
<td>41.6 (6.0)</td>
</tr>
<tr>
<td>Social Services   [National Norm]</td>
<td>19</td>
<td>4.6 (3.2)</td>
<td>18</td>
<td>18.4 (8.6)</td>
<td>18</td>
<td>39.9 (5.7)</td>
</tr>
<tr>
<td>Counseling</td>
<td>14</td>
<td>3.6 (3.3)</td>
<td>18</td>
<td>14.1 (9.2)</td>
<td>15</td>
<td>38.9 (4.5)</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>5.4 (4.5)</td>
<td>8</td>
<td>26.3 (9.2)</td>
<td>7</td>
<td>40.4 (7.1)</td>
</tr>
</tbody>
</table>

Based upon the responses to the MBI our respondents are not experiencing feelings of burnout at higher levels than those reported for the broader sample of health care workers. On the contrary the health care workers we interviewed generally showed higher levels of personal accomplishment and fewer feelings of depersonalization than the national comparative sample. Levels of emotional exhaustion were relatively higher than those reported on the other two scales, but they fell in the mid range of the normative sample distribution.

There are also minimal differences when comparing different occupational groups, with one possible exception. Persons working in counseling seem to be experiencing less emotional
burnout than other groups. Compared with respondents in other primary work areas, those working in counseling had the lowest mean scores on all three scales. Based upon a regression analysis of these data, the difference between counselors and other work groups is statistically significant on the emotional exhaustion scale (p<.001) and marginally significant on the depersonalization (p<.08) and personal accomplishment scales (p<.06). That is, to say, when compared to peers in other areas of work, counselors are less emotionally exhausted, feel less depersonalized but also feel a lower sense of personal accomplishment. The difference in means between the other professional work sector types interviewed (i.e. medical, social, mental health) are not statistically significant.

One can also compare levels on the MBI staff sample working in medical, mental health, and social service areas with national norms. Figure 1 suggests that levels of emotional exhaustion for respondents working in medical care and social services are close to national norms, and they may be somewhat better off having less feelings of depersonalization and a greater sense of personal accomplishment. Mental health workers (those who reported that their primary area of work was mental health) appear to be the one group where burnout may be higher than the national norm. When compared to national norms, mental health workers have above average scores on emotional exhaustion. They have levels similar to national norms on the depersonalization scale. However, mental health workers interviewed for this study have much higher levels of personal accomplishment than the national norm.
Table 5 presents mean MBI values for the three major occupational groups in the medical care area: physicians, nurses and dentists. While the differences are small, nurses demonstrate more evidence of burnout than physicians and dentists. They have higher mean scores on both the emotional exhaustion and depersonalization scales, and a lower level of personal accomplishment. The intergroup differences are not statistically significant.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Emotional Exhaustion</th>
<th>Depersonalization</th>
<th>Personal Achievement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td>9</td>
<td>17.2 (9.2)</td>
<td>5.2 (4.2)</td>
<td>40.0 (4.8)</td>
</tr>
<tr>
<td>Nurses</td>
<td>10</td>
<td>22.8 (10.8)</td>
<td>5.9 (5.4)</td>
<td>37.2 (6.0)</td>
</tr>
<tr>
<td>Dentists</td>
<td>6</td>
<td>20.0 (9.3)</td>
<td>4.7 (1.1)</td>
<td>42.2 (5.3)</td>
</tr>
</tbody>
</table>

We also investigated whether there were other professional or organizational variables that were related to the burnout scales. Table 6 presents mean scale values in terms of position in agency hierarchy. There are no important differences in burnout with respect to position in the agency hierarchy. Persons with supervisory responsibilities scored lower on the emotional exhaustion and depersonalization scales, but these differences did not approach levels of statistical significance. Further regression analyses were performed to test for associations between each MBI scale and age, gender, level of education, number of years worked, and employment in a hospital. None of these relationships were found to be statistically significant.

24
Age was the only socio-demographic variable to exhibit any significant association with even one subscale. Feelings of depersonalization and emotional exhaustion declined significantly with the age of the respondent.

In summary, the MBI did not support the common perception that staff working in HIV/AIDS service delivery in New York City are at a higher risk of burn out than other workers. We also failed to detect any systematic variation between MBI scales and several provider and organizational characteristics. In view of the content of the interviews with workers themselves however, it is possible that these scales fail to capture many stressors. To further explore the experiences of the respondents, we now turn to a summary of the qualitative component of the interviews.
### Table 6

<table>
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<tr>
<th>Position</th>
<th>N</th>
<th>Mean Score Depersonalization Subscale</th>
<th>N</th>
<th>Mean Score Emotional Exhaustion Subscale</th>
<th>N</th>
<th>Mean Score Personal Accomplishment Subscale</th>
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<tr>
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<td>84</td>
<td>19.9 (10.1)</td>
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<td>18.3 (9.2)</td>
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<td>39.2 (6.0)</td>
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<td>38.5 (7.7)</td>
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### Qualitative Analysis of the Staff Interviews

As presented in Appendix A, a broad number of areas were explored by the study team during the 86 interviews with HIV/AIDS workers. The interview transcripts yielded a voluminous amount of content for qualitative analysis. We are reporting here on three key aspects of this analysis: what do workers find most stressful/difficult about their work, what do they find most rewarding and what support systems and organizational changes would be most helpful to them.
The content analysis for these three areas was conducted by broad type of health professional in order discern differences by profession. The specific professional groupings for which a sufficient number of interviews existed to permit this type of analysis were physicians, nurses/nurse aides, social workers, counselors and health educators/outreach workers.

Broad Themes

A series of broad themes emerged across all types of professional care providers interviewed, though the frequency with which a certain theme was mentioned varied by profession. These cross-cutting themes included institutional and service system variables the fatal nature of HIV/AIDS, the relative youth of the persons afflicted, social stigma experienced by clients, the stress of maintaining confidentiality (especially when ethical concerns over secondary transmission were present), transference/identification with the client and fears of contagion - most notably not HIV/AIDS but tuberculosis.

Institutional and HIV/AIDS “System” Stressors

Health care providers confronting large caseloads of HIV positive patients often report not receiving positive feedback from their supervisors. Supervisors may lack needed managerial skills or may themselves be overwhelmed by work. Providers in stressful care settings, overwhelmed by the demands of their caseloads could benefit from constructive feedback from their supervisors or from a more formalized supervisory process.

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"I guess what I would want is for him (the supervisor) to say, it's talk about a case or something like that, I guess I would want more input from him as to what opinions I currently have, just some kind of dialogue and I don't have that with him... With him I would like more of that rapport. It's like I look to him for guidance like he's supposed to know everything about all the issues, but I tend to find I know more about all the issues than he does and that scares me because the sole responsibility just falls on me and I don't really have anyone to check with except my other coworkers who may have gone through that."

In addition, a cross section of providers report feeling frustrated by the HIV/AIDS service system. Providers report their anger over facing innumerable bureaucratic roadblocks while trying to get services for patients who are seriously ill. Many providers mentioned the overall "system" as an ongoing source of stress.

Specific bureaucratic entitites including the Division of AIDS Services were mentioned by numerous respondents as a factor contributing to their stress. Providers must also confront their clients' frustration as they too grow impatient with the pace at which their needs are met. One case manager shared his extreme frustration over trying to get benefits for patients who die before benefits could be secured for them.

"...I go through my stress in dealing with the situation, but they go through their own stress having to rely on a system that doesn't care about them and their illness. It would take a month to get out a check even though a client is suffering in an apartment that they don't like and they try to keep a client intact. Then for them to die, and you feel they didn't get what they justly deserved. It hurt and in all these situations that is what happened. So it hurt me more so this client didn't receive what I think they should have gotten."

Further contributing to provider stress are large caseloads many workers must carry.
In the face of a non-responsive bureaucracy the sheer size of caseloads can make obtaining even the most basic services unworkable. Moreover, many providers report that HIV/AIDS is often just one of a multiplicity of problems the patient and provider must confront.

"It is not enough to speak about AIDS... they have other issues that are affecting their lives. Child abuse, battery, these issues are serious and need to be addressed as well."

"There is too much to do and not enough resources to plug into. Unfortunately there isn't like a manual that you can go to for AIDS work which says in this case you do this.

Finally, other institutional variables specifically mentioned by respondents as stressful included lack of commitment on the part of the organization to providing high quality HIV/AIDS services, poor office space, and low salaries & benefits.

Poor Prognosis

AIDS has an extraordinarily high fatality rate, and this places an additional burden on health care providers who are trained primarily to treat, heal and cure disease. Studies of health care providers working with cystic fibrosis noted the unpredictable course of the disease and the hopeless prognosis led to an increased level of burnout among staff. Health care providers are often not trained to cope with the inevitable process of multiple/retenentless loss engendered by caring for HIV/AIDS patients.
"HIV and AIDS is a process of loss, as I observed it. It's just a continuum of loss. People lose their health. They lose their job. The family abandons them. They lose their self-esteem. I mean, it's just one thing after another. It's just a continuum of losses. Very rarely do you find somebody gaining or improving.'"

In addition to addressing the needs of the index patient, frequently health and social service providers working with HIV/AIDS patients are expected to provide social and psychological support to the patient's family and friends and to have long-term contact with them over the course of the disease. The complex nature of familial relationships further intensifies the stress faced by HIV/AIDS service providers.

Health care and social service providers are oriented toward sustaining life and supporting the patient, and some report difficulty in working with patients who will not recover. Working with terminally ill and rapidly deteriorating patients can provoke anger, depression, frustration and feelings of powerlessness. Providers often have minimal training in bereavement counseling, yet they are confronted both by the psychological needs of the patients and the needs of the families facing the impending death of loved ones.

"I was responsible for doing all the nitty-gritty stuff with the families, and I basically felt like a funeral director and funeral planner. I mean, I was burying probably two or three kids a month, trying to deal with the aftermath of the sibling, trying to deal with kids whose parents died first and it was just too much."

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Given the overwhelming fatality of HIV/AIDS and the steady decline in the patient's health status, one would assume that health care providers trained to "cure" diseases would find it difficult to feel any sense of personal accomplishment from an exclusively HIV positive caseload. However, many providers have learned to measure progress on small increments and report positive feelings of accomplishment in improving the client's situation. Provider felt that it was their job to help patients learn to live with HIV/AIDS.

"The best part of my job is making people feel good about the fact that they're living with AIDS, and I try to do that philosophically with all the patients that I work with...I say living with AIDS because people live with AIDS. Sure they die of a complication, but they live with this." Providers also report that being part of a team effort helps them to diffuse the stress of working with a uniformly fatal disease.

Social Stigma of HIV/AIDS

HIV/AIDS is a socially challenging disease for the United States, with transmission of the virus occurring in the context of intimate personal relationships, and often occurring in the context of relationships considered "unacceptable" by some. HIV/AIDS has brought about public scrutiny of private issues because the "disease has burdened private acts with social consequences." Although trained as care providers, many health professionals are unprepared to confront issues of sexuality and feel reluctant and ill-prepared to discuss specific
sexual and substance using behaviors. In CHAIN Technical Report #2, the survey found that training on sexual history taking was a priority for health care and social service providers.

Moreover, providers themselves often hold negative attitudes toward gay lifestyles or injection drug users which they must confront.

I'm a 42-year-old heterosexual man and all my life I've been taught that homosexuality is a sin, that it is not good. You know, these people are deviants and, suddenly, here I was. I will say that a good 35-40 percent of my caseload was gay males, and that was an issue where I had to come to terms with a lot of my staff and say, well, this has to stay on the side because this client needs some services. Here is a human being in need of services. But it was very hard for me at first.

In addition to coping with their own prejudices, providers report their distress as their patients are discriminated against by family, employers and others in their social networks.

Some providers noted that the institutional culture was not supportive of their clients' lifestyle and this added additional stress to the work setting. One provider addressed the issue of stigma by saying that the stigma is based on the fact that HIV/AIDS is a disease of marginalized people.

"AIDS is now a disease of disenfranchised and marginalized people, many of whom are at the margins of society, in which there is a stigma that at first was a stigma based on reactions towards homosexuality. And today, it's a stigma based on reactions towards marginalized people. Many of these marginalized people are gay men, but many of these people are IV drug users and poor people who just happen to be in the wrong place at the wrong time, and a lot of unfortunate people who do not have the resources to deal with an epidemic which is possibly
one of the worst medical scenarios a person can be in."

Providers also noted that despite being well into the second decade of the epidemic, HIV/AIDS is still surrounded by secrecy and shame. Providers felt that the stigma attached to HIV/AIDS negatively impacted their work.

"Here, (the institution), AIDS is something that represents shame, it represents secrecy, it represents what it's negative about lifestyles...I'm struck by the universal hostility towards the disease, no matter what the ethnic background, no matter what the racial background of the community. It's amazing that with the exception of the gay community...everyone else looks at AIDS in a way in which it's not embraced."

Finally, a number of providers expressed not being able to talk about their work with family members and friends because of their (family members and friends') perception about HIV/AIDS and those who get it. Many felt that unless people had a personal connection to HIV/AIDS, they had no ability to understand the stresses, challenges and fulfillment of working with HIV/AIDS.

"... that aspect of what I've learned depresses the hell out of me, but makes me realize that human beings are human beings and that the only way that people respond to the disease in a productive way is if they know someone who's had it, where they know someone who's died of it, and then people will rise to the occasion. But until that happens, it's still us against them."

HIV/AIDS remains a socially stigmatized disease and a disease that may create a sense of isolation for both the patient and for the provider. Social support is capable of "moderating"
stressful life events and may be a major factor in determining an individual's level of vulnerability. A cross-cutting factor which mediated some of the stress of working with HIV was a supportive partner or family, or supportive coworkers.

Over Identification/Counter-Transference

The health care and social service providers interviewed for this study reported being intensely involved with the needs of their patients. Many providers have personal experience of the HIV/AIDS epidemic, reporting the loss of family members, friends, or colleagues. In the interviews, providers report a special connection to HIV/AIDS, and this connection can be a double-edged sword. More than other disease conditions, HIV/AIDS service providers often described the difficulty of maintaining the boundary between the professional and the personal realms.

Providers report going to funerals, planning funerals, feeling like the family member to their patients and becoming very personally involved with their patients. Many of the interviewees have made providing services to their HIV positive clients a personal crusade and regularly exhaust all personal and professional resources at their disposal to achieve their goals.

"I knew him from the streets and he followed me into the office. That means he wants help, and I'm gonna get it for him, no matter what, no matter how many phone calls I've got to make. If I've got to call every colleague, if I've got to pull in favors, I'm going to get him help, and that is..."
Some providers report confronting their own fear of death in the context of caring for patients. Other providers who have worked in the field for more than 10 years, worry that they have become "too distant" in an effort to protect themselves from more loss and bereavement.

It is noteworthy that a substantial proportion of those interviewed were moved to tears during the sessions. Frequently the tears began as the interviewee tried (often for the first time ever), to articulate the impact of the epidemic on them personally. Most of the interviewees remarked that the staff interview provided a welcome outlet for their feelings of sadness and grief.

**Youth of Patient:**

Ninety percent of agencies surveyed in the initial Personnel Needs Survey reported increased caseloads, and providers continue to see increased numbers of HIV positive patients. Many HIV/AIDS providers are in the same age range as the patients they treat, adding to issues of "counter-transference. The youth of the patients becomes a vehicle for many providers to "over-identify" with the patient and may bring up feelings of mortality and vulnerability among providers.

"We've all got to die. But the impact is—for example, our coworker was too young to die. That's the bottom line. And there is a lot of people over there that are infected and young: 25, 24, 28, 30. There are
people over there that they are young, female, pregnant, infected."

"for someone who is younger, in their 30's and 40's, it is a little harder for me, because they are my contemporaries. I mean it pulls on those strings that I don't want pulled."

The uncertain progression of the disease, and the surety of pain and disability in younger patients is especially stressful for providers. Many providers reported that HIV/AIDS in children was the hardest to cope with, and reported difficulty in dealing with pregnant mothers and pediatric HIV/AIDS cases. One physician believed that tubal ligations should be mandatory for all HIV-positive women, while another wondered how HIV-positive women who are having babies could be so stupid. Although these views were rare, the research team was surprised to hear them articulated in this fashion by service providers in New York City.
Fear of Infection

Given the heavy media emphasis on risks of occupational transmission it is surprising that the fear of being infected by HIV/AIDS through contact with patients and clients is not a large concern. Health care workers in high HIV/AIDS prevalence settings report a strong awareness of the risks of occupational transmission, however the risk of tuberculosis, especially of drug resistant strains seems a much more pressing concern.

In our interviews, most health care providers report little worry of transmission of HIV/AIDS during normal procedures and routine patient contact. Educational efforts in hospitals and training settings have promoted a feeling among health care providers that they have the knowledge necessary to prevent infection and transmission. However, many of the same health care providers will admit that friends and family members remain anxious about their patient contact. The anxiety of family members and close friends may add to the stress that health care providers experience. Many providers also report that the re-emergence of tuberculosis has impacted their interactions with patients. Some providers acknowledged avoiding entering the rooms of patients known to have active tuberculosis and expressed concern that their organizations were not doing enough to prevent the spread of tuberculosis. One provider had been infected with tuberculosis due to inadequate infection control procedures at her agency.
Confidentiality

HIV/AIDS as a disease has forced discussion of private and intimate acts into the public eye through the link between sexual and drug use activities and the transmission of HIV. HIV/AIDS has also raised critical issues of civil liberties which some view in conflict with traditional public health tools of infectious disease surveillance and control. Confidentiality requirements for HIV/AIDS designed to protect patients against discrimination place additional strains on care providers incases where the revelation of an individual's HIV status may protect others from infection. While physicians may disclose HIV status to a third party affected they are not bound to do so. Other health professionals cannot disclose to a third party at immediate risk of HIV through a partner.

"I feel this urgency to warn people because I know they're at risk, or I have privileged information and I know they're at risk and they may or may not know they're at risk. It's something that I have no control over and it's really scary."

The stress of maintaining confidentiality can also stem from a choice on the part of the patient not to have his or her status revealed to family members, a spouse or a partner who may be involved in giving care. In interviews with home health nurses, respondents said that not being able to tell the partner who is caring for the infected individual to use universal precautions or not to have unprotected sex adds a moral and ethical dilemma to their interactions in the home.

Rewarding Aspects of Working with HIV/AIDS
Rewarding Aspects of Working with HIV/AIDS

Although many respondents reported a number of negative aspects of working in HIV/AIDS, most were highly motivated individuals dedicated to HIV/AIDS service work. Some reported feeling "called" to HIV/AIDS work, and despite the fatal nature of the disease, they enjoyed making a difference in patients' lives. Many providers talked about how personally committed they were to working with HIV positive clients, and the positive impact that working in the epidemic had upon their lives. Across professional category, providers felt privileged to work closely with their clients, and felt that they had close personal relationships with these clients.

"You know, you really get the chance to see - you're led into the lives of people where you otherwise wouldn't ever venture. And sometimes that trip is very exciting and gratifying and sometimes its horrifying. And it's a privilege that I have that I don't take for granted."

"And my patients are like family, and I want them cared for like I would want my mother or father cared for and so that's why."

"...the intensity, the intimacy, the level of involvement thars possible when you're working with people confronted by a life-threatening illness...helping people to die, that makes sense to me."

Many of those interviewed were inspiring to listen to as they conveyed their professional commitment to caring for HIV positive individuals until a cure is found, or until the end of their own lives. An almost religious sense of mission pervaded many of the interviews.
Support Mechanisms

One key component of the interviews was the question of what prevents burnout and what reduces stress in the workplace. Institutional variables which caused stress included, large caseloads, bureaucratic red tape and poor supervision. For some providers, simple recognition of their efforts and a positive word from their supervisors could make their work easier. For respondents with good supervisors, the role of the supervisor was mentioned repetitively. Good supervision was viewed as a key variable for minimizing stress.

Among the tools commonly used by providers to manage stress were informal and formal networks of support. Many respondents felt that they needed the opportunities to talk with their families or colleagues to “decompress.” A number of providers felt that it was important to be able to laugh and joke about work. One respondent commented “if we did not laugh, we’d always be crying.” Laughter was mentioned in many settings and by a wide variety of professionals.

Interviews suggest that making HIV/AIDS care part of the normal range of health care and social services provided will help to de-stigmatize the services and those who provide the services. Agencies which had mixed caseloads seemed to report less difficulty with staff retention and recruitment.
Retaining committed providers of HIV/AIDS services and preventing burnout necessitates the development and promulgation of institutional policies which support the delivery of quality care to HIV/AIDS patients. Physicians and other medical providers interviewed report that although their institutions give good quality care "so much more could be done." Health care providers state that the institutional attitude toward HIV/AIDS, either written or unspoken, can be a great stress to them as they attempt to provide services in an environment which does not support their efforts.

Institutional supports including training, staff support groups, days off for mental stress, employee recognition, multi-disciplinary teams to meet the needs of HIV/AIDS patients, and a flexible staffing schedule. Specific incentives which reduce staff turnover and staff stress are being studied in the context of New York City HIV/AIDS service agencies. Research suggests that a mix of training programs to prepare providers to deal with HIV/AIDS coupled with incentive programs to persuade providers to stay in the field are important components.

Results by Profession

In addition to the broad themes which cut across health professional groupings the study team undertook a qualitative analysis within the health professional groups for which sufficient interviews were available. This approach permitted a separate analysis for physicians, nurses/nurse aides, counselors, social workers and community outreach workers/educators.
The analysis was conducted to identify those aspects of HIV/AIDS work which health professionals most frequently describe as negative or positive. In addition, the analysis sought to identify health professional recommendation for supports which could be put in place to improve the work environment for their profession.

**Physicians**

Table 7 presents a summary of the seven interviews with physicians. In general, the greatest negatives from the physicians' perspective included all of the cross cutting themes mentioned above, such as the youth of the patients, fear of tuberculosis, identification with patients and the fact that the disease is incurable. In addition to these cross cutting issues, some unique negatives were highlighted by them as well. A number of physicians discussed aspects of their peer relationships and institutional context as negatives. For example, some described feeling supported within the unit by other HIV/AIDS workers but feeling isolated from the hospital overall. One physician describes himself as the only physician who was doing HIV/AIDS work in the hospital and therefore, feeling very isolated. With regard to his colleagues doing similar work in other institutions, he felt that a competitive atmosphere among doctors has begun to prevail in the HIV/AIDS arena which has negative implications for collegial interaction.

*Two of the physicians interviewed were openly gay men who described their difficulty*
maintaining boundaries (again the counter-transference issues and their “survival guilt” after watching so many of their fellow gay men die.

One physician was deeply concerned over the lack of a traditional public health approach to the HIV/AIDS epidemic. From his perspective, the STD model should have been applied earlier on. He believed that the epidemic could have been markedly curtailed through this approach. The same individual felt that one of the negatives of HIV/AIDS work was that it attracted “less intelligent” physicians. He stated his concerns as follows: “I think you have a group of physicians that have gotten on the HIV bandwagon and they make a handsome living of it; these are the ones that put the patients in the hospital six to eight weeks at a time get all kinds of consultations”. This physician was concerned that persons with HIV/AIDS were receiving “over intervention”.

A number of physicians expressed concern over working with problem patients who are seeking unnecessary drug prescriptions and have a history of intravenous drug use. One physician after describing the positive aspects of working with many people with HIV/AIDS states, “the other side of it is that you meet a lot of people who you want to kill, who you want to throw out a window”. This particular quote depicts the level of vehemence that some health professional feel when interacting with some patients.

The final negative which was highlighted by some physicians was “over accessibility”
to patients, either their own accessibility or that of their colleagues. One female physician describing her supervisor comments, “there’s a lot of stress. Some of it she puts on herself because she’s so conscientious in that she gives them her beeper number so that many of them are constantly in touch with her outside during the weekend until 11 o’clock at night.”

The overriding theme that came across in the physician interviews was the medical impotence associated with treating the terminally ill. Physicians, more than any other health professional group interviewed seem to experienced the greatest angst associated with this dilemma. This is logical given the fact that physicians see their role as curative unlike the traditional roles of other types of health professionals.

Finally, it is noteworthy that some physicians became very moved while discussing the negative and positive aspects of the HIV/AIDS epidemic from their perspective. Indeed, for some it appeared to be the first time they had reflected upon and actually verbalized the impact over time that the epidemic has had on them personally. One physician stopped talking for a long time, began to cry, apologized above his tears and began again stating, “if this thing was happening to my people, it would be different–it would just be different”. This young white male physician then elaborated on the overwhelming toll that the epidemic was taking in the poor minority communities which he serves and highlighted the fact that society seems to not have mobilized adequately to avert the devastation which is occurring as a result the widespread
prevalence of HIV infection in poverty communities.

With respect to the positive aspects of working in the HIV/AIDS epidemic, a number of themes came through in the physician interviews. Most important was assisting patients in living longer by intervening to prevent illnesses and treating illnesses as they occur. A number of physicians indicated enjoying the intellectual challenge that HIV care presented. Other physicians expressed pride in their work, described positive experiences with mentors, superiors and colleagues, and noted that caring for patients with this illness makes one a better person. Finally, physicians talked about confronting and "embracing" the epidemic. As one physician put it, "it's been a very long road and I had decided from the beginning I wasn't going to run from it; I was going to run toward it."

Physicians mentioned a number of supports which could be put in place to improve their working conditions. The need for psychotherapy and support groups, expanded HIV/AIDS training that addresses the range of available services and adequate salaries for HIV/AIDS work were all suggested. In regard to institutional and organizational supports, physicians felt generally supported though one indicated great concern over the inadequacies of TB precautions at this institution and a number felt "isolated" in their delivery of HIV/AIDS care.
<table>
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<tr>
<th>Stressors of HIV Work</th>
<th>Positive Aspects of HIV Work</th>
<th>Supports for HIV Work</th>
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<tr>
<td>Fear of TB</td>
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<td>Support groups</td>
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<td>Over identification with patients</td>
<td>Caring for the patients</td>
<td>Higher salary</td>
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<td>Sense of personal growth</td>
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<td>Intellectually challenging work</td>
<td>Good colleagues</td>
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<td>Take pride in my work</td>
<td>Working as a role model</td>
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<td>Professional Isolation</td>
<td>Extending patients' lives</td>
<td>AIDS training</td>
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<td>Patients seeking unnecessary drugs</td>
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<td>Separate AIDS patients from other patients</td>
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<td>Complex needs of patients</td>
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<td>Working with IVHQs</td>
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<td>Survivor guilt</td>
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<td>Over-medicalization</td>
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<td>TB precautions are inadequate</td>
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<tr>
<td>Attracts less intelligent physicians</td>
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</table>
Nurses/Nurses Aides

Table 8 presents a summary of the interviews with 11 nurses. Nurses identified similar negatives to those which appeared in the cross-cutting broad themes including fear of tuberculosis, the youth of patients and the lack of an effective treatment for HIV/AIDS. However, additional negatives raised by nurses included interacting with patients “from the street”, the emotionally draining aspect of working with people with HIV/AIDS and the sense of feeling alone and overwhelmed. The difficulty in dealing with patients who were very angry, the complexity of working with patients who were “noncompliant” with treatment regiments and the problems of managing confidentiality concerns were also repeated themes.

“It’s draining, overwhelming. I feel useless. You know because we are doing so much, yet we do know that whatever we do is not going to have any effect to the outcome. You know we can do it. It hurts. It bothers me. It drains us all and we don’t have any type of vent system, we’re in there and we’re trying to be professionals, but we hurt too. We want to be part of the bereavement process.”

For one nurse in her 60’s who spends a great deal of time in HIV counseling, providing HIV positive results was identified as the worst aspect of her job. This same nurse participated in a support group which she characterized as “sad” because the group talked constantly of the grief of the patients and of the caregivers. She thought it was important to develop some form of intervention that did not focus on the negative aspects of working with people with HIV/AIDS.
With regard to the positive aspects of working with HIV, nurses had many similar responses to those of physicians. However, in contrast to physicians, nurses were much more likely to mention how much satisfaction they received from making a difference in the lives of their patients (i.e. enjoying small successes), loving the work and liking the patients. One nurse who expressed her sadness at giving people HIV positive results, felt that the best part of her job was giving negative results and providing HIV/AIDS prevention education.

A number of support mechanisms were identified by nurses which would help improve their ability to enjoy their work and to provide the highest level of quality care. These included instituting programs to increase staff interaction, mechanisms to allow health care workers to talk about the stresses and strains they experience in a nonthreatening atmosphere. Some expressed concern over a support group in which the supervisor was a participant.

The need for additional training in HIV/AIDS and the opportunity to attend training was highlighted by a number of nurses. Also highlighted was the need for additional funding for degree education. This was a particular concern among LPN's who waged to earn BSN degrees. The common practice of requiring the employer to make the initial financial outlay and later be reimbursed is a strong fiscal disincentive to obtain baccalaureate education among the nurses interviewed. Organizational issues which could be addressed with appropriate policy initiatives
included the chronic problem of under-staffing, the lack of organizational support and again the need for institutionalized programs of training and educational support.
<table>
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<th>Species of HIV Work</th>
<th>Positive Aspects of HIV Work</th>
<th>Supports for HIV Work</th>
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<td>Lack of cure</td>
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<tr>
<td>Fear of infection</td>
<td>Making a difference</td>
<td>Support groups</td>
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<td>Youth of the patients</td>
<td>Patient Relationships</td>
<td>Training</td>
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<td>Non-compliant patients</td>
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<td></td>
</tr>
<tr>
<td>Homophobia</td>
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</tr>
</tbody>
</table>

Organizational issues

Lack of organizational support
Educational support
Bad support groups
Under-staffing
Social Workers (MSWs)

Table 9 presents a summary of the interviews with five social workers. The negatives aspect of working with HIV and AIDS expressed by social workers were similar to those elicited from the other professional groups. The unpredictable nature of the disease, the youth of their clients, the possibility of exposure to TB and watching their clients physically deteriorate all contribute to the emotional strain experienced by these social workers. Of particular interest, however, was the sense from three of the social workers that the culture of HIV/AIDS professionals demands a level of commitment that is unhealthy. True commitment can only be demonstrated by being a “hero” to the clients and the agency or by overextending oneself financially and emotionally.

Two social workers also identified inter-professional conflict as source of stress at their jobs. One of the social workers found that doctors did not understand nor did they appreciate the work she performed for the patients. Doctors often pressured her to discharge patients even when she had been unable to fully complete ambulatory service arrangements. Another social worker found that the nurses she worked with did not appreciate the level of expertise that she brought to helping patients cope with emotional and psycho-social issues. The nurses believe that any willing and compassionate ear can adequately meet the psychological needs of any patient.
Overall, social workers seemed committed to the HIV/AIDS service, but expressed a professional level of concern and a healthy awareness of the pitfalls of counter transference. Social workers had the skills to seek out professional assistance and supervision when supportive supervision was not available on the job. Social workers expressed concern for their patients, but seemed to have an ability to separate their work and their personal lives. They also did acknowledge that HIV/AIDS work had taken a toll on their personal lives. The social workers interviewed were near uniform in expressing the importance of maintaining boundaries between their personal and professional lives. Good supervision and time away from work were also mentioned as important for maintaining high level job performance.

Social workers may be more adequately equipped to combat workplace conflict and stress because of the graduate training they have received. They report a concern for the high caseloads they bear and the heavy burdens placed upon social workers is an epidemic which is a medical tragedy and a social environmental disease. Their status as post graduate level professionals provides them a sense of career mobility and multiple opportunities to move into other social service arenas.
Table 9 - Issues for Social Workers

<table>
<thead>
<tr>
<th>Stress of HIV work</th>
<th>Positive Aspects of HIV work</th>
<th>Supports for HIV work</th>
</tr>
</thead>
<tbody>
<tr>
<td>TB</td>
<td>Making a difference in clients' lives</td>
<td>Maintaining boundaries</td>
</tr>
<tr>
<td>Youth of patients</td>
<td>Unique process to be allowed to share</td>
<td>Time off away</td>
</tr>
<tr>
<td>Physical deterioration of clients</td>
<td>Personal growth</td>
<td>Training</td>
</tr>
<tr>
<td>Feeling of helplessness</td>
<td></td>
<td>Informal sharing/discussion</td>
</tr>
<tr>
<td>HIV – mothers</td>
<td></td>
<td>Good supervision</td>
</tr>
<tr>
<td>Death of clients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor system for obtaining services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unpredictability of disease</td>
<td></td>
<td></td>
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<tr>
<td>Having to be a hero</td>
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<td></td>
</tr>
</tbody>
</table>

**Organizational Issues**
- Large caseloads
- Tensions among other professionals (doctors/nurses)
Counselors

Table 10 presents the positive and negative aspects of working in HIV/AIDS as reported by six counselors. Among the counselors, the one negative aspect which was highlighted was the problem of high case loads and the preponderance of paperwork. Positive aspects of working with HIV clients reported by counselors include enjoying educating the clients and obtaining services for clients. As with the nurses, counselors have a strong sense of fulfillment from their work, feel that they are making a difference in the clients' life and experiencing a strong sense of personal accomplishment. Many counselors felt that working with HIV positive patients had made them better people, and more open to others.

"It's very enlightening to me and very frustrating when I look at a woman who has never really cared about herself or taken care of herself...when that begins to change or all of a sudden they, I know it becomes a cliche...but when they become empowered and say 'wait a minute!' I want to do something with my life I want to take care of me, I like to see that."

"I think it's basically made me and it sounds corny but it's made me a better person, it's really made me more understanding."

Counselors reported that giving HIV positive results was particularly difficult, and they were relieved that most of the test results they gave were negative. However, the issue of the inevitable fatality of HIV/AIDS is a pressing concern for counselors who feel that they are on the front line of the HIV/AIDS epidemic which is increasing in number.
"It's horrible, just so horrible (giving positive results). It's the thing that I dread. I had to do one this week, and I have a second one too."

"I had one woman, honest to God, I gave her the results and she tried to jump out the window. I had to call Psych ER."

"The uniquely stressful part is that, you know at some point whether it's 5 years, ten years, or next month, that ultimately this person will be dying from the virus or what this virus will do to them."

"I guess the realization is that we're not going to be put out of business at any time in the near future...it's gotten to the point where I'm now totally numb to the numbers...it is so sad. I taught history, we are condemned to repeat it if we don't learn from it, and with AIDS it looks like that's what's happening...it's very scary."

Similar to other professionals, the uniform fatality of HIV/AIDS was a stressful aspect of working with HIV positive clients. Some counselors noted the strain on both their own work and the work of their colleagues.

"I've seen people come and go, different types of personalities, again it's like we're sitting here talking about my history of death, other people are so afraid of death. You know they just can't face it. They can't see people suffering without lowering the boundaries and getting too involved, that is the most important thing, keeping boundaries."

Some counselors felt that working with injecting drug users was particularly difficult. One issue that was specific to drug users, was the perception of counselors that the patient might come in, obtain services and supplies and turn around and sell the supplies on the street.

Counselors felt it was stressful to have people tested and not be able to give them their results.
"I think the most difficult are the IV drug users to talk to. I guess because many times they sing a good song but as far as putting that into reality, they'll tell you anything you want to hear."

Strategies highlighted by counselors for reducing the stress of HIV/AIDS work include having a good relationship with one's supervisor, having access to personal counseling, therapy and support groups, having faith/religion and working in an atmosphere where there are supportive co-workers. The need to maintain the separation between work and one's personal life was also mentioned.

The organizational factors which added to stress of counselors are also enumerated in Table 10. Factors worthy of note are poor supervision, lack of institutional support for work, high staff turnover and low salaries.
<table>
<thead>
<tr>
<th>Stresses of HIV work</th>
<th>Positive Aspects of HIV work</th>
<th>Supports for HIV work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social stigma of AIDS</td>
<td>Educating clients</td>
<td>Training</td>
</tr>
<tr>
<td>Client deaths</td>
<td>Client gratitude</td>
<td>Good Supervision</td>
</tr>
<tr>
<td>Working with HIV+ mothers</td>
<td>Religion/faith</td>
<td>Counseling Therapy for provider</td>
</tr>
<tr>
<td>AIDS paperwork</td>
<td>Meeting clients needs</td>
<td>Support groups</td>
</tr>
<tr>
<td>Giving HIV+ results</td>
<td>Seeing change in clients' attitudes</td>
<td>Faith/religion</td>
</tr>
<tr>
<td>Community denial</td>
<td>Relationships with clients</td>
<td>Supportive Co-workers</td>
</tr>
<tr>
<td>Physical deterioration of clients</td>
<td>Feeling as if making a difference</td>
<td>Maintaining separation between work and personal life</td>
</tr>
<tr>
<td>HIV+ family members</td>
<td>Sense of fulfillment from work</td>
<td>Supportive partners/spouses</td>
</tr>
<tr>
<td></td>
<td>Strong sense of personal accomplishment</td>
<td></td>
</tr>
</tbody>
</table>

**Organizational Issues**
- Large caseloads
- Pressure to deliver numbers
- Lack of agreed upon job description
- Agency disorganized
- Funding and services disappearing
- No space
- Lack of institutional support for the work
- Target population
- Staff turnover
- Low salaries
- Geography of agency
Case Managers

As indicated in Table 11, the 11 case managers had similar sources of stress as counselors. Case managers described their long and personal relationships with clients and reported absolute frustration in battling the system to obtain client services. Some case managers talked about the frustration of dealing with patient anger.

"...the bureaucracy is extremely stressful, all the way up the line. When a patient becomes angry with you, you know because you did whatever you had to do or something didn’t work out and they’re blaming you. I had one patient tell me he’s going to shoot me in the head a couple of times. I told my superiors."

Case managers often became personally involved with clients and would go to extremes to obtain services and entitlements. One case worker said, "you don’t want to know how I get it done, but I get the services and that’s what matters."

Sources of stress mentioned by case managers included the difficulty of working with the Division of AIDS Services and the fact that HIV concerns were only one of many issues that the case managers must address for their clients. Case managers talked about the stress of dealing with issues of death and coping with the emotional needs of the families who are often in varying stages of denial and acceptance. Case managers feel a conflict between offering hope to their clients and helping them to make legal and care taking arrangements for the family.
"How can you not care about somebody who's dying, who's got children, whose family, whose mother or father are standing there, they're falling apart... you tell me what is more painful? Is it more painful to offer hope when there's no hope? Or is it kinder, more benevolent, more merciful to tell somebody, you really should make arrangements, because your daughter is going to die."

Case managers also had similar concerns regarding organizational factors which contribute to a stressful environment. They highlighted lack of training and low salaries. The positive aspects identified by the case managers were very similar to those identified by the counselors and other health care workers, including patient relationships, giving hope to clients and making a difference in clients' lives.

Case managers identified a number of factors which could reduce the stress of working with HIV positive clients. Case managers expressed feeling that they are on the frontline with clients and that their supervisors need to recognize their work. They also stressed co-worker support as a critical issue in continuing their work.
### Table 11 - Issues for Case Workers

<table>
<thead>
<tr>
<th>Stresses of HIV work</th>
<th>Positive Aspects of HIV work</th>
<th>Supports for HIV work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client deaths</td>
<td>Relationship with clients</td>
<td>Training</td>
</tr>
<tr>
<td>Working with OAS</td>
<td>Meeting client needs</td>
<td>Co-worker support</td>
</tr>
<tr>
<td>Client denial</td>
<td>Sense of fulfillment from work</td>
<td>Maintaining separation between work and personal life</td>
</tr>
<tr>
<td>Paperwork</td>
<td>Strong sense of personal accomplishment</td>
<td>Good supervision</td>
</tr>
<tr>
<td>Social stigma of AIDS</td>
<td>Making a difference in clients' lives</td>
<td>Counseling therapy for provider</td>
</tr>
<tr>
<td>AIDS is one of many problems</td>
<td>Giving clients hope</td>
<td>Exercise</td>
</tr>
<tr>
<td>Time constraints</td>
<td>Feeling as if they can improve the quality of life for clients</td>
<td>Traint approach to client care</td>
</tr>
<tr>
<td>Physical deterioration of clients</td>
<td></td>
<td>Having a supportive family</td>
</tr>
<tr>
<td>HIV - co-workers</td>
<td></td>
<td>Peer support</td>
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<td></td>
<td></td>
<td>Recognition for work done</td>
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</table>

**Organizational Issues**
- Feeling the agency does not support work
- Large workloads
- Agency is disorganized
- Funding cuts
- Lack of training
- Organizational communications
- Low salaries
Community Outreach and Education Workers

The 11 community outreach and education workers interviewed had very similar sources of stress associated with working with HIV positive clients to those expressed by the other professional groups. Some education and community outreach workers spoke with a passion about the need to “be there” to educate the youth of tomorrow. One education worker talked about the need to reach her community and to hug her clients.

Recognition that AIDS education is an important prevention tool made these workers take their jobs very seriously as they took their message to the streets. Some outreach workers remarked that New York City is the “vanguard” of HIV/AIDS education. Workers talked about going to crack dens, city parks where prostitution is common and of creating a safe space for clients to talk about their fears.

As shown in Table 12, outreach education workers indicated the importance of training in reducing the stress of working with clients. Desired topics include HIV updates, information on women’s issues and bereavement. Unlike other health professionals responding to the interviews, outreach workers and health educators were more likely to indicate that their agency was isolated and needed to make linkages with other agencies. Outreach workers and community health educators also mentioned low salaries as a source of organizational stress.
<table>
<thead>
<tr>
<th>Stresses of HIV work</th>
<th>Positive Aspects of HIV work</th>
<th>Supports for HIV work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional exhaustion</td>
<td>When client's condition improves</td>
<td>Good supervision</td>
</tr>
<tr>
<td>Coping with client anger</td>
<td>Relationships with clients</td>
<td>Training</td>
</tr>
<tr>
<td>Issues around disclosure</td>
<td>Empowering clients</td>
<td>Working as part of a team</td>
</tr>
<tr>
<td>Working through client denial</td>
<td>Personal growth</td>
<td>Counseling therapy for providers</td>
</tr>
<tr>
<td>AIDS one of many problems</td>
<td>Making a difference in client's life</td>
<td>Time-off/mini vacations</td>
</tr>
<tr>
<td>Uncooperative &amp; apathetic clients</td>
<td></td>
<td>Recognition for work done</td>
</tr>
<tr>
<td>Youth of clients</td>
<td></td>
<td></td>
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Organizational Issues:
- Agency lacks linkages with other organizations
- Personal conflicts
- Lack of resources
- Organizational policies
- Staff turnover
- Low salaries
- Geography of agency
DISCUSSION

The study results presented here are from a series of in-depth personal interviews as well as quantitative burnout inventories with 86 randomly selected health professionals working in HIV/AIDS. What is striking about the study results is the disjunction between the relatively positive results from the quantitative analysis of the MBI and what had routinely been assumed to be the level of burnout and stress among those working in HIV/AIDS. As indicated above, previous studies have found an association between working with a population with a high fatality rate and the probability of burnout. In contrast, for this population of health care workers, the Personal Accomplishment subscale of the MBI exceeds national averages for the reference group. Scores on the Emotional Exhaustion subscale are equivalent to the national averages and scores on the Depersonalization subscale are considerably less depersonalized. While these health professionals described multiple sources of stress associated with HIV positive clients during their interviews, these same professionals also enumerated many positive aspects of working with persons affected by HIV and AIDS. The group of professionals also generated a significant number of suggestions about which institutional factors could be altered to decrease the stress level as well as specific job factors which could be modified to reduce stress.

The fact that this randomly selected sample of health professionals working with
HIV/AIDS did not demonstrate higher levels of burnout than a national reference group may be explained by a number of factors. The study team believes that a significant amount of selection bias exists with regard to those health professionals who elect to work in HIV/AIDS. The vast majority of those interviewed indicated that they had chosen to work in HIV/AIDS as opposed to having been assigned by their employer to an HIV/AIDS unit or activity. The health professionals interviewed were highly motivated to provide service to HIV/AIDS clients with only a few notable exceptions. Almost uniformly the sample of health professionals viewed themselves as doing something important, perhaps accounting for the high score on the personal accomplishment subscale of the MBI. Table 13 presents the questions which are used in the MBI to measure the three key domains - personal accomplishment, emotional exhaustion and depersonalization. It is possible that the high level of personal satisfaction and sense of accomplishment found among health professionals in AIDS is acting to moderate the effects of the other two domains measured on the MBI, emotional exhaustion and depersonalization.

One common theme expressed by many of the health workers interviewed was a sense of their awareness of the ultimately poor prognosis of their HIV-infected clients. This awareness has apparently lead many of those interviewed to develop a more realistic set of expectations for defining success in HIV/AIDS work. In short, most of those interviewed seemed to accept small victories: a case worker succeeding in improving the housing situation for a client, a physician successfully intervening to reduce the impact of an opportunistic infection; or a social worker...
succeeding in working with a family to achieve disclosure and acceptance of a diagnosis. It also appeared that health care workers viewed themselves as on the “front line” of a worldwide disaster. Their sense of seeing themselves as contributing to the fight against a disease which has already devastated many parts of the world and multiple communities in the United States contributes to a sense of self-esteem about their work despite the fact that small victories remain the norm rather than major breakthroughs. The study team asked most of those interviewed how those in their social circle felt about their type of work. Contrary to our expectations, most found that their social circle respected their choice of work. In short, working in HIV/AIDS is socially valued in liberal circles and may in fact be broadly valued by society.

(Text continued on page 68)
<table>
<thead>
<tr>
<th>HOW OFTEN</th>
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<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every day</td>
<td>Never</td>
<td>A few times a year</td>
<td>Once a month</td>
<td>A few times a month</td>
<td>Once a week</td>
<td>A few times week</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional Exhaustion</th>
<th>Personal Accomplishment</th>
<th>Depersonalization</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel emotionally exhausted from my work.</td>
<td>I can easily understand how my recipients feel about things.</td>
<td>I feel I treat some recipients as if they were objects.</td>
</tr>
<tr>
<td>I feel used up at the end of the work day.</td>
<td>I deal very effectively with the problems of my recipients.</td>
<td>I've become more callous towards people since I took this job.</td>
</tr>
<tr>
<td>I feel fatigued when I get up in the morning and have to face another day on the job.</td>
<td>I feel I'm positively influencing other people's lives through my work.</td>
<td>I worry this job is hardening me emotionally.</td>
</tr>
<tr>
<td>Working with people all day is really a strain for me.</td>
<td>I feel very energetic.</td>
<td>I don't really care what happens to some recipients.</td>
</tr>
<tr>
<td>I feel burnt out from my work.</td>
<td>I feel exhilarated after working closely with my recipients.</td>
<td>I feel recipients blame me for some of their problems.</td>
</tr>
<tr>
<td>I feel frustrated by my job.</td>
<td>I can easily create a relaxed atmosphere with my recipients.</td>
<td></td>
</tr>
<tr>
<td>I feel I'm working too hard on my job.</td>
<td></td>
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</tbody>
</table>
The fact that the HIV/AIDS workers in this study were low on the depersonalization subscale did not surprise the study team. Repeatedly the health care workers described their difficulty in maintaining boundaries and controlling countertransference with regard to their clients. This seemed to be most pronounced among those who themselves identified strongly with the clients because of their similarity in age, cultural background or sexual orientation. The literature on HIV/AIDS service providers previously cited and additional on-going work suggests that HIV/AIDS services is characterized by over personalization in comparison to the level of personalization which occurs generally among other populations receiving services. In other words we argue that these workers start from an extreme level of personal connectedness and commitment to HIV positive client population.

We now turn to the most important element of the discussion that is, what the results offer with regard to initiatives which might improve the quality of the work situation for health care workers in HIV/AIDS and thus the quality of services to clients. We largely believe that the results of the interviews strongly support those of the systematic survey reported in the CHAIN Technical Report #2. There are a number of innovations in the workplace which can greatly improve the quality of work for those in HIV/AIDS. Those issues that seem to be important to all categories of the professionals are the need for expanded training, having a sense of organizational support and a network of peers (i.e., counteracting isolation). For counselors, case managers and mental health workers the need to have a manageable caseload and the supportive
The interviews with health professionals were occurring at the same time that a series of funded support groups were underway at many of the sampled institutions. Those interviewed provided anecdotal information about the support groups. In general the greatest criticism was that at some institutions the immediate supervisor was part of the support group, which some staff, particularly junior staff, felt was an obstacle to the efficacy of the support group. Others expressed concern that the support groups became depressing, focusing on the saddest aspects of the work and some commented that although they would have liked to attend support groups they did not have the time to do so. However, the need for a forum to facilitate peer support within the institution and across institutions was a theme which repeatedly emerged. It may be worthwhile to explore the efficacy of regionalized support groups where the support group participants are from multiple institutions so that a greater degree of anonymity is achieved. For obvious reasons many participants were reluctant to discuss personal issues that were affecting their work in the context of the group given the presence of close colleagues. Developing policies and protocols to minimize institutional stresses and to encourage a supportive work environment should be a top priority for human resource planners.

The interviewers were also struck by the frequency with which those interviewed
would become emotionally moved often to tears as they described the impact the epidemic has had on them. Many of those interviewed have been on the front line for 10 years or more. For them the cumulative toll of the epidemic has been considerable. It is possible that there exists a substantial subset of HIV/AIDS workers which could benefit from one-to-one counseling. It is noteworthy that a number of those who expressed emotional distress in the course of the interview had not previously explicitly articulated how they felt about the epidemic. Many respondents appeared to be experiencing their true feelings for the first time. Ironically some members of the study team had the impression that physicians may be most in need of counseling services since they may feel the greatest degree of frustration over their impotence in regard to the epidemic. Substantive programs which address the emotional toll of the epidemic on health care workers appears to be a priority area across all health professional categories.