



A Division of the New York Legal Assistance Group

LegalHealth
Professional Partnership to Promote Well Being

Impact of Legal Interventions on Cancer Survivors©

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**LegalHealth Study Confirms that
Legal Interventions Are an Essential Component of Care for Cancer Survivors**

Executive Summary

LegalHealth undertook a study of the impact of legal services on the lives of fifty-one of its clients with cancer. The results of our study show that:

- Legal problems for patients with cancer are a significant nonmedical need that must be addressed to maintain quality of life during and after cancer treatment. Seventy-eight percent of the survey clients reported that having cancer created their legal difficulties.

- Legal interventions impact cancer survivors in the following ways:
 - 83% of the survey clients reported that legal services helped to reduce their worries and stress

 - 51% of the survey clients reported that legal services had a positive affect on their financial situation

 - 33% of the survey clients reported that legal services positively affected their family or loved ones

 - 22% of the survey clients reported that legal services helped them to keep medical appointments

 - 23% of the survey clients reported that legal services helped them to maintain their treatment regimens

- Cancer specialists need to be trained on the legal issues affecting their patients.

- Legal advocacy services need to be made more widely available to people with cancer just as they have been for people with HIV/AIDS, geriatric patients and other vulnerable patient populations.

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Background

The National Cancer Institute reports that the estimated 10.1 million cancer survivors in this country represent a tripling of the number of survivors from 1971 to 2002. With the increased rate of survival for people diagnosed with cancer comes an increased need to adapt to the intense financial, emotional, practical and health consequences associated with living with the illness.

LegalHealth, a division of the New York Legal Assistance Group, helps patients cope with the myriad of life changes brought on by the disease and its treatment by providing free legal services to cancer patients and other patients with serious or chronic illnesses. LegalHealth fulfills its mission by building upon the trust already established between a health care professional and a patient. By working within that existing bond, LegalHealth attorneys are able to help doctors and other healthcare professionals gain an understanding of the nonmedical needs of their patients, and work to resolve the legal issues that negatively affect their patients' health and quality of life.

LegalHealth attorneys operate weekly or monthly legal clinics at New York City area hospitals and community-based organizations. The typical legal issues our clients with cancer and other chronic illness face involve government benefits, housing conditions, disability benefits, insurance coverage, immigration, end-of-life planning, debt management, accessible housing, special education, home care services, and employment matters. Generally, the hospital's physicians or social workers refer patients to the legal clinic. In addition to the clinics, LegalHealth educates healthcare professionals to recognize significant issues that may negatively impact medical outcomes but have a legal remedy.

The Study

With financial support from the Lance Armstrong Foundation and the Center for Disease Control, LegalHealth undertook a study of the impact of legal services on the lives of 51 of our clients with cancer. This report describes the results of that study.

In order to determine the impact of our legal representation on our clients' lives, LegalHealth, working with law students enrolled in a public interest law seminar, a professional nonprofit evaluator, and a public health researcher specializing in cancer, developed a survey consisting of 15 questions. Once the final version of the survey was completed, we sent letters to our clients with cancer asking if they would be willing to participate in a survey that was designed to gather information about our services in order to help us determine how we might improve them. The letter explained that the survey was confidential, that it would be conducted by law students and volunteer lawyers over the telephone and that it should take no longer than 10 to 15 minutes. The letter also explained that any client who did not wish to participate in the survey should simply tell the interviewer when she called. Four law students and a volunteer lawyer spoke with a total 51 clients. Each interviewer asked the same questions and completed a survey form

for each client who was interviewed. Some of the questions asked how the client had heard about the availability of legal services and where the initial meeting with the LegalHealth lawyer had taken place. Other questions related to the client's specific legal needs as well as the effect that receiving legal services had on the client's life.

Our data showed a demographic trend of more women than men as clients of LegalHealth, a trend toward more non-married people, a sense that having cancer had adverse financial consequences on persons from different socioeconomic backgrounds, a theme of near total client satisfaction, and the sense that having a legal advocate directly decreased a client's stress level. (A full 76% of our survey pool was female, 84% were U.S. citizens, and only 20% were married. The age of the clients ranged from 29 to 82 with 59% being between the ages of 40 and 59. At least 43% of the clients were categorized by LegalHealth as "white, non-Hispanic." For 21% of the survey pool, there was no information regarding ethnicity in their files

Some of our client interviews were rather stoic and brief, while others were very emotional and moving. No matter the tone, the surveys collectively revealed that the services LegalHealth provided to these clients were welcomed, needed, and appreciated. An overwhelming number of those interviewed, 83%, reported that having a legal advocate directly decreased their level of stress. This finding strongly suggests that the mental health of people with cancer can be positively impacted by the provision of legal services. Through a variety of mechanisms legal interventions were shown to reduce client stress and bolster emotional stability by making the client feel supported as well as improve fundamental quality of life issues.

Legal Challenges Facing People with Cancer

The clients we spoke with had faced, or were facing, a variety of legal issues. Sixty-one percent had grappled with two or more legal issues. For 78% of the clients, especially those seeking help with debtor/creditor problems, disability benefits and job discrimination, their cancer diagnosis had, in effect, created their legal difficulties. For example, Clients S-6 and T-4 had problems with creditors only as a result of receiving treatment. Client S-10 had health insurance through work, but he lost his job after being diagnosed. Client S-7 had been busy with his family and young children, and the need for a will had not occurred to him before he was diagnosed. Client T-6 had been making \$33,000 per year and had not needed public assistance until her financial situation deteriorated along with her health. For those who said cancer had not been the direct cause of their legal predicament, their compromised state of health exacerbated their legal situation.

Financial Concerns

Many clients in the survey pool stated that they could not afford a lawyer. Several were subsisting primarily on Social Security or receiving other forms of public benefits such as public assistance and Medicaid. Others had lost their jobs and, therefore, their main source of income. Fifteen clients, or 29%, were dealing with debtor/creditor issues. The survey responses suggest that while not all of the clients would be classified as “poor” by federal standards, many struggled financially. Whether trying to fend off creditors calling for payment or attempting to continue to work despite health complications, our survey showed that the financial implications of having cancer left many of these clients in an extremely vulnerable state.

Telephone calls from creditors seeking payment was a problem for many clients with financial concerns. Calls from bill collectors seemed to reach a level of near-harassment. Client E-3 reported being worried every time the phone rang. Client S-6, who was hospitalized eight times in one year, could not keep up with her medical bills. The phone calls began after the anesthesia department sent her bills to a collection agency. "Even my kids were scared to take the phone," said Client T-2. For Client E-3 LegalHealth was able to bring the harassing phone calls to an end. Client S-2 reported that her lawyer called her creditors, explained her situation to them, and the telephone calls ceased. Regarding her creditors, S-2 said, "they would listen to him, but they wouldn't listen to me." Client S-6's lawyer contacted the anesthesia department and convinced them to reduce the bills and create a payment schedule. Client E-1's medical debt was reduced to \$2,000 from \$26,000.

Three clients sought advice regarding public assistance. Client E-2 was told that she qualified for aid under the "safety net assistance" program. Client T-2 was still in the process of trying to obtain food stamps at the time of the survey, but LegalHealth was successful in obtaining food stamps for Client T-6. When asked if the LegalHealth lawyer had helped, Client T-6 replied:

Oh, yes. They [public assistance] were terrible to deal with. They did not answer my phone calls. By having NYLAG help me, people got right back in touch with me and things were done. Only because of their assistance did I get the help that I needed.

Disability Issues

Clients in the survey pool who sought help with disability benefits were generally in need of Social Security Disability, Supplemental Security Income, long-term disability, or short-term disability. Client S-5 required SSD when she was no longer able to work due to lymphedema which caused her right arm to swell to triple the size of her left. According to Client S-5, "SSD has really saved our lives." For Client T-6, LegalHealth handled phone calls to the Social Security office, which meant a great deal to her. "These phone calls were stressful to me..." Client T-6 explained, "I was on the phone all day when I should have been resting."

Health Insurance

Those clients who had problems with health insurance were usually seeking assistance with Medicare, Medicaid, or COBRA. In a number of cases significant problems had already developed by the time LegalHealth became involved. For example, when Client S-10 came to LegalHealth he was without health insurance after he lost his job. On the other hand, LegalHealth was able to help Client E-2 get Medicaid and to prove to Client T-6's medical provider that she was covered by COBRA at the time she had received health services. When asked if LegalHealth had helped her with COBRA, Client T-6 said, "Oh my God, yes. They were able to get in touch with [the hospital], go back to the dates that I was being billed for, and resolve that I was covered for that time, even though the claims were not put in (because I was dying)."

Workplace Issues

Four of the clients surveyed sought help for job discrimination or accommodation issues. While all four reported that LegalHealth provided needed assistance, three of them ended up leaving or losing their jobs. When Client S-5 tried to go back to work, she discovered that her job had not been kept open for her despite the fact that she still had leave time available. She eventually agreed to a settlement because of her lymphedema. Client S-9 worked in the human resources department of a hospital and sought accommodations at work. In her view, LegalHealth was "very helpful," but her bosses had "beaten [her] down" and she eventually left work. Client S-10 received advice and assistance in drawing together a declaration to submit to the E.E.O.C., but lost his job anyway. Client T-3 is still in the process of getting help and has been documenting all of the instances of discrimination she has experienced at work.

Advance Planning

LegalHealth addressed the advance planning needs of 18 (or 35%) of the clients in the survey. The services provided included drafting wills, preparing powers of attorney and establishing legal guardianship for minor children. All of the clients who received legal assistance with advance planning felt that LegalHealth helped them and/or their loved ones with their legal needs. Client C-11 expressed relief that the power of attorney she received from her terminally ill aunt enabled her to handle the personal affairs of her wheel-chair bound relative who was too weak to leave her home. While 35% of the clients in the survey received help with advance planning matters only nine clients in this group came to LegalHealth solely for assistance with advance planning. As noted above, most clients in the survey, 61%, were facing two or more legal issues at the time they were referred to LegalHealth.

Effect of Receiving Legal Services

In response to general questions about how legal services had affected their lives, clients discussed the reduction in stress, gaining peace of mind, and the general feeling of having someone on their side. Client S-3 observed that lawyers can "see their way through the thicket of bureaucracy," and others seemed relieved that LegalHealth was specifically dealing with the bill collectors. Client T-3 said she has positive feelings about LegalHealth because the lawyer working with her "understood me and really was fighting for me." Several noted that because of

LegalHealth's services, they were able to spend more time focusing on themselves and their illness. Client E-1 said that because she had received help with her legal dilemmas, she was not only "able to sleep at night," but she felt more knowledgeable and powerful. Others said that receiving legal services "gave me my life " and "really picked me up; I was beside myself." Client T-4 said that, "A lot of doors closed when I got the cancer, but then people at CancerCare and [the LegalHealth lawyer] . . . I just started living again. Becoming part of the world. Back to normalcy."

Stress Reduction

Eighty-three percent of the clients surveyed answered "yes" in response to the specific question "Did receiving legal services help reduce your worries?" Client T-6's answer was an emphatic "Oh my God, 110%." Client S-3 said that, "knowing that I had help from what appeared to be a very competent and heavyweight legal person, that always helps. I don't know why, but it seems that lawyers are respected. It's like having an ally." Eleven of the 51 clients surveyed explicitly stated that receiving legal services helped them keep their medical appointments, and 12 felt that legal services helped them maintain their treatment regimen.

Impact on Financial Situation

Fifty-one percent of the clients surveyed said that receiving legal services had affected their financial situation. As noted above, Client E-1's medical debt was reduced from \$26,000 to \$2,000. " Client S-6 noted that without LegalHealth's assistance, it would have taken her two additional years to pay off her medical bills; "I felt like I was never going to get finished before, and I was thinking, I was going to have to declare bankruptcy." Because LegalHealth's services are free, many clients reported that they did not have to deplete their family resources to get the legal help they needed. Client T-6 declared that the legal services "made me able to live with a roof over my head and food to eat."

Impact on Family and Loved Ones

Thirty-three percent of the clients surveyed felt that receiving legal services had positively affected their family and loved ones. Client S-6's mother had someone to call when she had questions about her daughter's medical debt, and she could spend more time at her job and more time caring for daughter. Client S-2 thought legal services helped her adult son because he knew she was getting help with her debt problems. Client S-5 said she was no longer "such a nut," and no longer worried that she would have to sell her house. Client E-2's nine- and thirteen-year-old boys ended up receiving public assistance, and E-3's and T-2's young children no longer had to fear harassing creditor phone calls. Thirty-nine percent reported that receiving legal services had no affect on their loved ones.

Impact on Mental Health

The survey responses underscore the fact that providing free legal services to people with cancer has a positive impact on mental health. Not only was the overall stress level of many of clients reduced, but the feeling that they were no longer dealing on their own with a "mammoth," "faceless" bureaucracy is apparent. It is not surprising then that more than 90% of the clients we spoke with would recommend LegalHealth to other people diagnosed with cancer.

The Growing Need for Legal Services in Medical Contexts

In dealing with the intense financial, emotional, practical and health consequences of cancer detailed in the preceding sections, patients and survivors clearly need the support of more than doctors, nurses, and social workers. One is left wondering why lawyers are not considered part of this healthcare team when the non-health side effects of a long-term illness like cancer, including medical and credit card debt, job discrimination, and the frustration of dealing with an often faceless, bureaucratic system, can have such a detrimental impact on well-being.

Although the fact that people with cancer need legal services has not been acknowledged on a wide scale, the importance of providing legal services to other vulnerable patient groups is accepted. Geriatric patient groups receive legal services in the area of estate planning and guardianship issues.¹ The correlation between housing, for example, and child health is receiving national attention.² Perhaps the most striking example of advocacy efforts on behalf of a patient group has been for people with HIV/AIDS whose legal needs have been recognized and funded since the early 1980's.³ The Centers for Disease Control and Prevention has indicated that a referral to legal services is among the first things that should be provided to people when they learn that they are HIV-positive.⁴ Our study revealed that the clients we spoke with faced most of the identical legal needs as people with HIV/AIDS, and that LegalHealth was able to assist in addressing many of them.

There are many benefits to multidisciplinary collaboration. Combining legal services with health services helps ease the patient's burden of receiving multiple services from distinct entities. Collaboration allows oncology specialists from different professional backgrounds the opportunity to enrich their practice by gaining knowledge of the various legal and mental health issues associated with cancer. For oncological social workers, specifically, the availability of legal services allows them to focus on their primary mission which is to address their clients' psychosocial needs. Finally, there are potential cost savings to healthcare institutions when the number of missed treatments decreases and when insurance entitlements are discovered to reimburse the hospitals for their services.

Lawyers should become part of the comprehensive, or holistic, team that supports people with cancer. As mentioned above, combined efforts between patients, doctors and lawyers have already had great success for people with HIV/AIDS, and there is a demonstrated need for such collaborations on behalf of people with cancer. Social workers and doctors make a great team and, with the addition of lawyers, almost all of a client's needs may be met.

¹ Bassuk K, Lessem J: Collaboration of social workers and attorneys in geriatric community based organizations. *J Gerontol Social Work* 34:93-108, 2001

² Zuckerman B, Sandel M, Smith L, et al: Why pediatricians need lawyers to keep children healthy. *Pediatrics* 114:224-228, 2004

³ Retkin R, Stein GL, Draimin BH: Attorneys and social workers collaborating in HIV care: Breaking new ground. *Fordham Urban Law Journal* 24:533-566, 1997

⁴ Revised Guidelines for HIV Counseling, Testing, and Referral (MMWR: Morbidity and Mortality Weekly Report, 50:RR-19 (November 9, 2001)

Conclusion

LegalHealth's success proves that lawyers can be integral in alleviating the myriad of nonmedical issues that so often result from a cancer diagnosis. While the lawyer's role in what is typically regarded as a health or medical situation may not be obvious, it is needed. In this era of exorbitantly priced healthcare, we have heard from clients who felt that they had no place to turn and no one on their side.

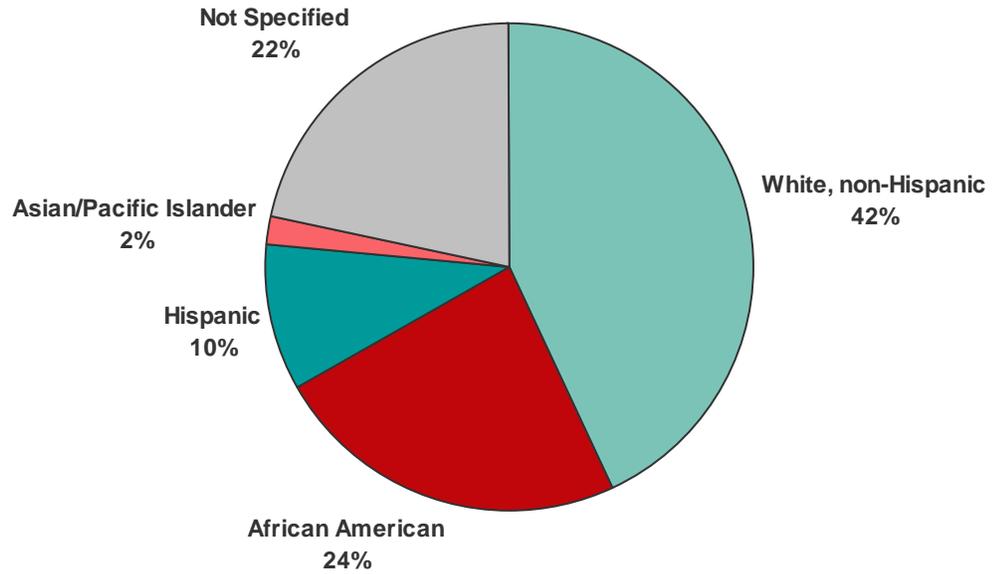
Many people living with cancer do not recognize that their needs are legal, and even when they do, they may not be able to afford the services of a lawyer. An organization such as LegalHealth can help clients and oncological advocates work through the nonmedical side effects that result from illness. Research, drawn from expert studies and from our own survey, shows that the mental health of people from many socioeconomic backgrounds who have cancer or other debilitating, long-term illnesses can be improved through the provision of free legal services. Ultimately, with the help of a healthcare team that includes a lawyer, a person with cancer can focus on what matters most – getting better.

(See attached charts)

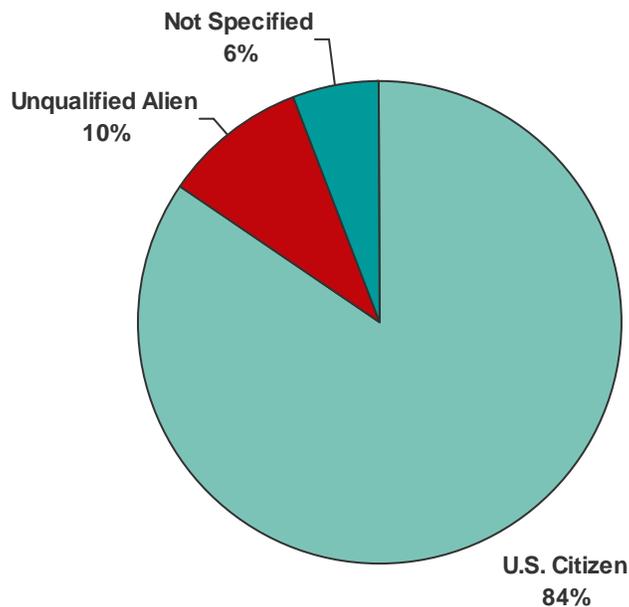
Attachment A

DEMOGRAPHICS OF SURVEY PARTICIPANTS

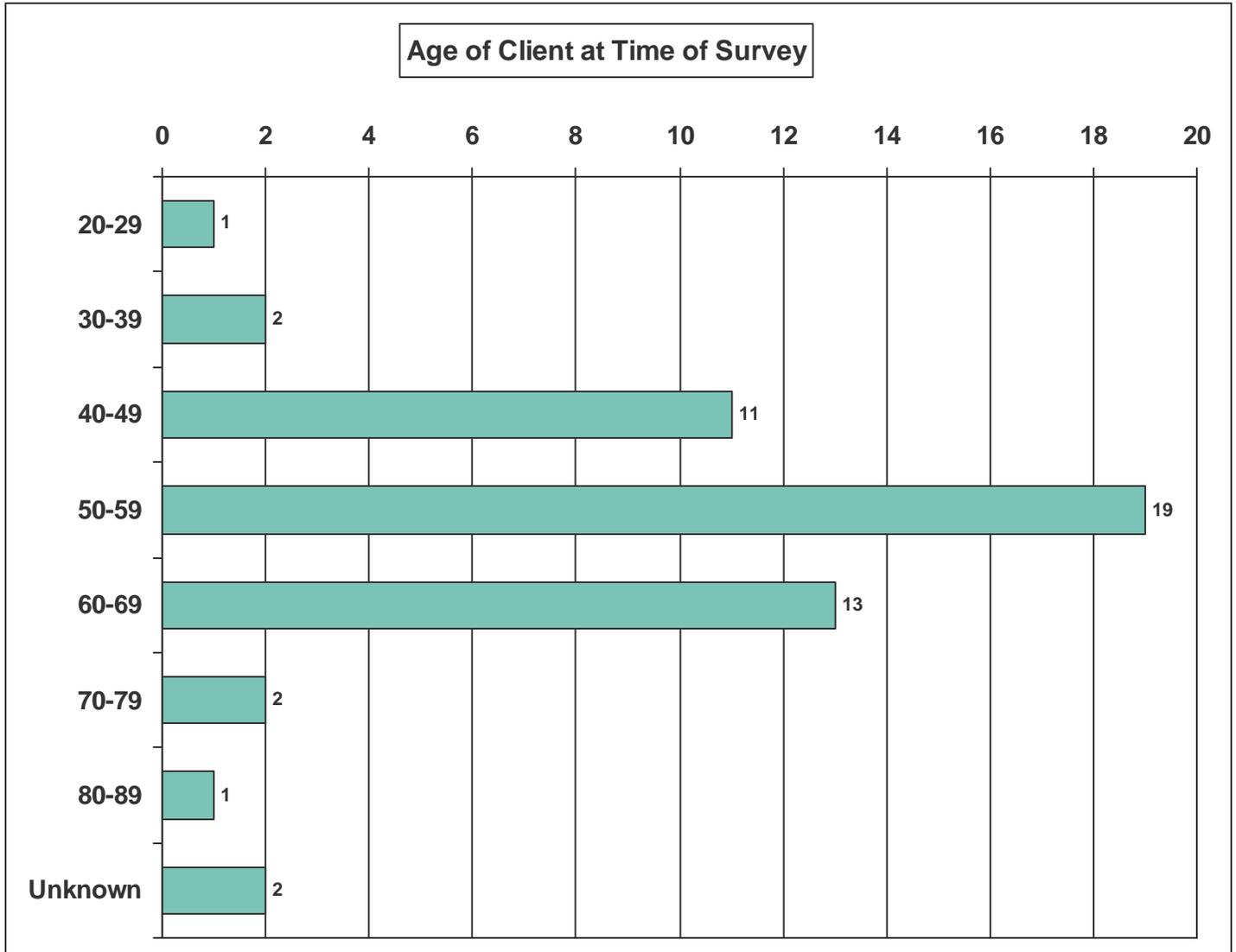
Ethnicity of Participants



Immigration Status of Participants

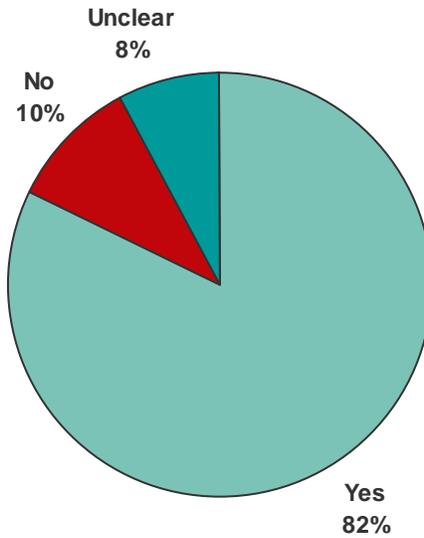


CLIENT DEMOGRAPHICS, cont'd.



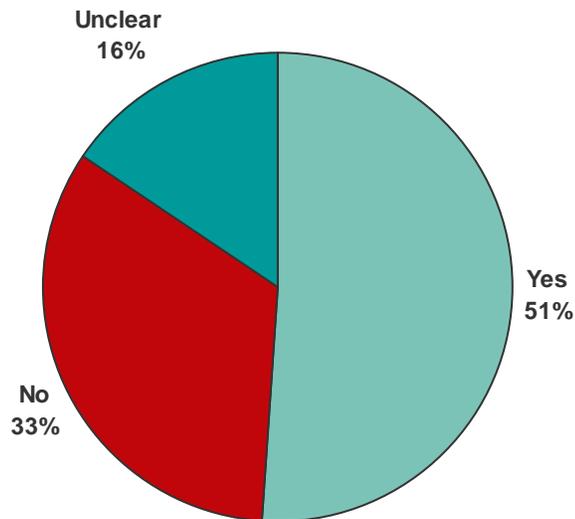
Attachment B EFFECTS OF LEGAL SERVICES

Did Legal Services Help Reduce Client's Worries?



Yes No Unclear

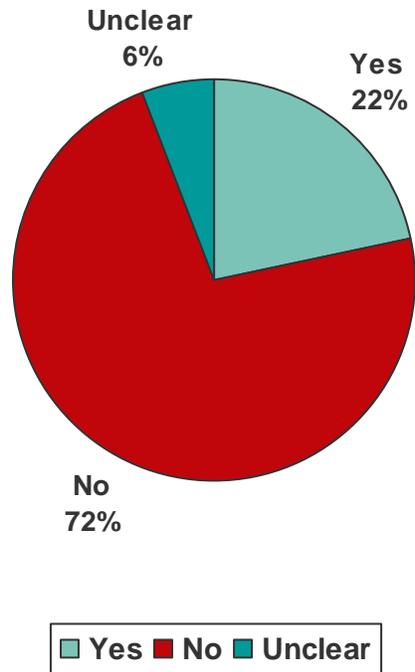
Did Legal Services Affect Client's Financial Situation?



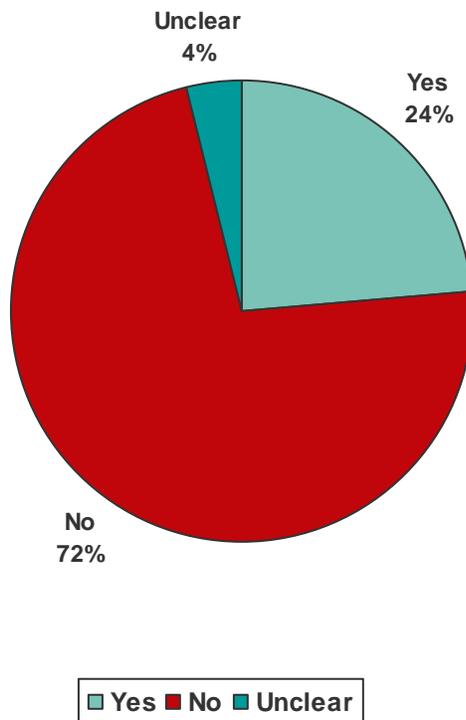
Yes No Unclear

EFFECTS OF SERVICES, cont'd.

Did Legal Services Help Client Keep Medical Appointments?



Did Legal Services Help Client Maintain Regimen?



EFFECTS OF SERVICES, cont'd.

