

The Family Ties Project is a six-year old multi-agency, collaborative demonstration project in Washington, DC that provides legal and mental health services to families affected by HIV/AIDS to enable them to plan for the future care and custody of their children. Through partnership with case management agencies, the Family Ties Project provides training and resources to case managers on end-of-life care and permanency planning.

A pre-training assessment instrument was used to measure case manager practice and attitudes with respect to future care and custody planning issues to provide baseline data for project evaluation and program planning. Approximately two-thirds of the surveyed providers were case managers, 15% were family advocates, 6% were supervisors and 31% were Master's-prepared social workers. Of the MSWs, 28% were licensed, and 74% of these were at the LGSW level and 20% at the LICSW level.

An analysis of the pre-training assessment instruments revealed that social workers/case managers are unlikely to routinely initiate discussion of issues relating to end-of-life care and permanency planning; they also are unlikely to routinely initiate a discussion relating to many of the barriers to planning future care and custody of a client's children. Master's-prepared social workers were generally no more likely than non-MSWs to initiate these discussions (Figures 1 & 2).

Often, case managers have large caseloads that may be a barrier to discussions concerning future care and custody, though providers indicated that lack of time is not a barrier (Figure 3). There was a slight difference, although not significant, between MSWs and non-MSWs concerning comfort level of discussing permanency planning issues with clients. There is a significant difference ($p < .05$) between the self assessment of MSWs and non-MSWs in terms of having the skills necessary to discuss these issues.

The experience of social workers is not unlike those of other members of the interdisciplinary team that provide care to persons with HIV. A recent national study of persons with HIV/AIDS found that less than half had communicated with their medical provider about end-of-life issues and that fewer than 38% had completed advance directives¹. Black and Latino clients and those with lower education levels were less likely to have had these discussions or to have completed advance directives.

Patients with a higher degree of social support, more positive coping skills and less denial were more likely to have completed advance directives. Patients with longer provider relationships and those with more trust in their providers were more likely to have discussed end-of-life care. Women communicated more with practitioners, as did patients who had children in their households. Overall, the researchers note that there has been little improvement in the proportion of HIV-infected individuals who have completed advance directives since studies in the late 1980s. It also is important to note that an increasing number of people with AIDS come from groups least likely to engage in advance care planning. Barriers that prevent clients from completing permanency plans were not identified in this study; however, the six year's experience of the Family Ties Project shows that parents and caregivers may take several years to make future care and custody plans and that completion of plans often is not a high priority during times of good health.

While this study focused on the relationship between the patient and health care provider, the findings are relevant to social workers and case managers. Women and people with

children in the home are more likely to have a discussion about advanced care and planning; however, these discussions do not appear to lead to the completion of needed legal plans and documents. People with higher social support and coping skills and with less denial are more likely to finalize plans. Social workers/case managers can provide this support as well as referral to resources that may facilitate clients' plans for future care and custody of their children.

Further investigation is needed to understand the barriers to routine discussion with clients about future care and custody issues. As treatment guidelines and standards of care continue to be developed, inclusion of future care and custody issues should be considered. Issues of access to legal services, as well as supportive laws and policies (e.g., standby guardianship, recognition of "non-traditional" families), should be considered.

Further information on the Family Ties Project is available at www.familytiesproject.org.

Figure 1. Self-reported frequency of case manager initiation of discussion with clients by psycho-social topic

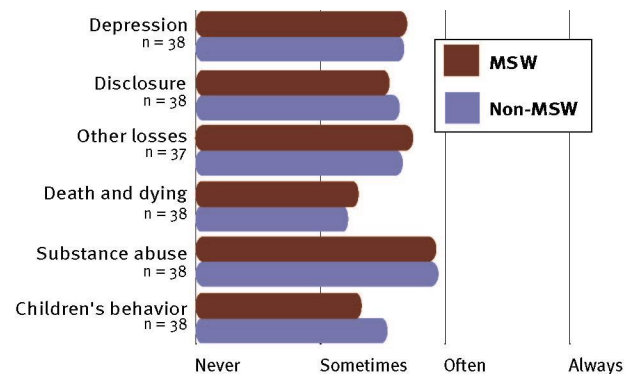


Figure 2. Self-reported frequency of case manager initiation of discussion with clients of future care and custody issues

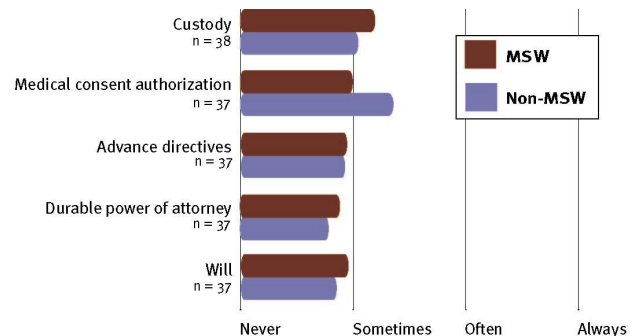
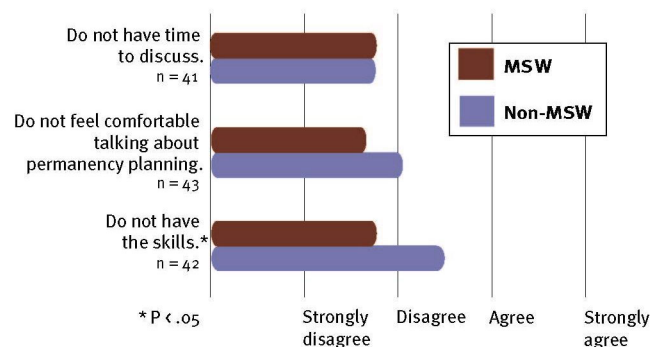


Figure 3. Self-reported case manager attitudes and skills relating to discussing future care and custody issues with clients



¹ Wegner, et. al. "End of life discussions and preferences among persons with HIV." JAMA. 2001;285:2880-2887.