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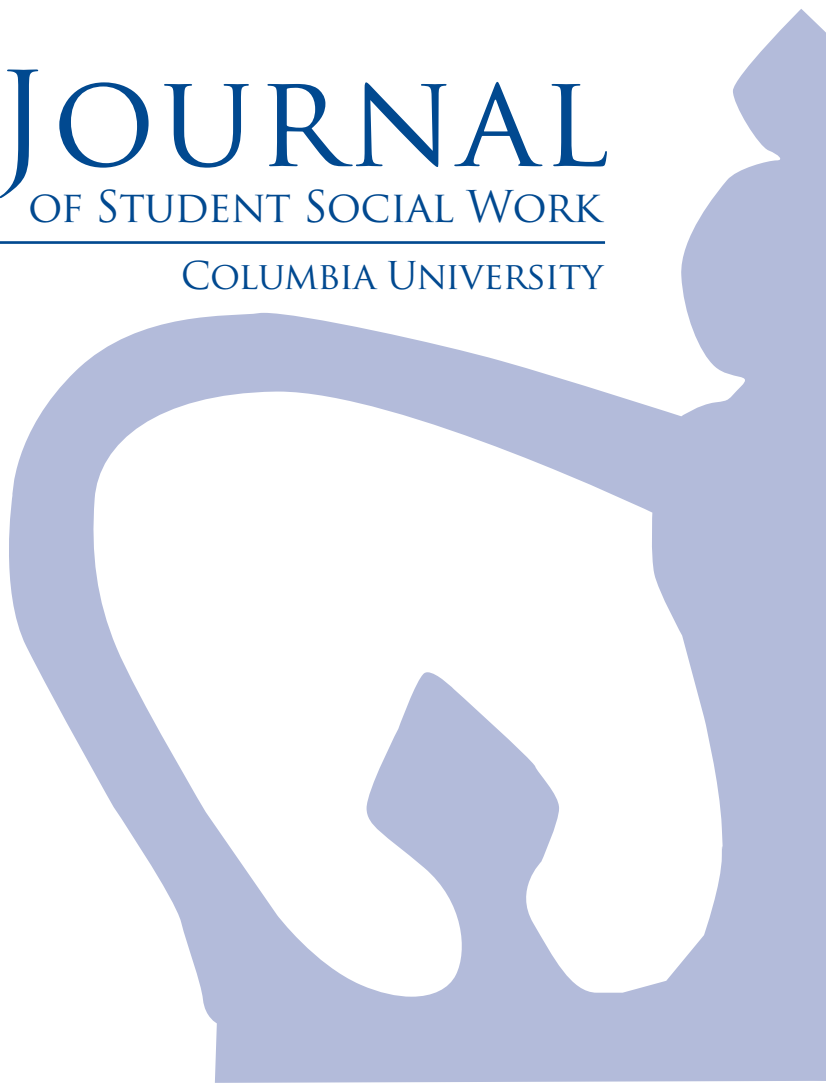


# JOURNAL

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The views expressed by the authors are solely their own and do not necessarily reflect those held by the Editorial Board or *Columbia University School of Social Work*.

Welcome to the fifth volume of the *Journal of Student Social Work at Columbia University*. This year's *Journal* includes six articles that reflect both the past and future of the field of social work. The included articles illustrate the ways in which today's social workers continue to examine traditional social work issues in new and innovative ways as well as the ways in which social workers are responding to contemporary issues in the field of social work.

The first article, by Ian Holloway, examines the current state of mental health diagnosis, treatment, and intervention strategies with Latino children.

The continuing challenge of how to most effectively support survivors of domestic violence is discussed in two of this year's articles. Elizabeth Brown considers the intersection of the domestic violence and child welfare movements, paying particular attention to the burden that both of these movements place on women, while Colleen Cary, Gabrielle Gervais, and Grace Song consider the challenges that domestic violence survivors face in obtaining safe and secure housing.

Recent legislation and its implications form the basis of consideration for two of this year's articles. Taimur Khan and Devika Iyer examine how the Anti-Prostitution Pledge impacts the physical health of commercial sex workers throughout the world, while Jennifer Zaleski explores the role of social workers in end-of-life care using Oregon's Death with Dignity Act as a starting point.

Finally, Natasha Nalls addresses both the complexity and the necessity of disclosing a child's HIV-positive status to both the child and the child's support system.

Each of these articles speaks to the continuing evolution of the field of social work. We hope these articles provoke discussion, inspire debate, and encourage new ways of approaching and understanding critical issues in the field of social work.

Sincerely,  
The Editorial Board

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*The Editorial Board would like to thank the Columbia University School of Social Work students and faculty, especially our Advisory Board, for supporting the Journal in its fifth year of publication and making it an integral part of the student experience at CUSSW. We are indebted to Jennifer Bellamy, Editorial Board Member 2005 and 2006, for her continued support and unwavering dedication to our blind review process. We would also like to thank Morgan Russell for her expert layout and design skills, as well as Dr. Alice Miller and Jennifer Friedman for their invaluable and insightful contributions to this year's Journal.*

Ian Holloway

*Research suggests that Latino children are at an elevated risk for a variety of mental health problems (Flores, Fuentes-Afflick, Barbot, et al., 2002). Latinos are often vulnerable to the deleterious effects of poverty, institutional racism, community violence and other types of psychosocial stressors, which have been linked to negative mental health outcomes (Flisher, Kramer, Grosser, et al., 1997; Saunders, Resnick, Hoberman, et al., 1994). Furthermore, Latino children are likely to face significant barriers to accessing mental healthcare services, such as limited availability of Spanish-speaking providers, difficulty obtaining and navigating health insurance, and cultural obstacles, such as the belief that mental illness is a spiritual or religious matter. The current paper will: (1) explore specific risk factors for mental health disorders among Latino children; (2) examine barriers to appropriate mental health treatment among Latino children; (3) provide an overview of the types of intervention strategies currently used to address mental health problems among Latino children; and (4) offer recommendations for the development of additional and/or improved methods for the prevention and treatment of mental health disorders among Latino children.*

There are more than 11.6 million Latino children living in the U.S., compromising the largest minority group of children in this country (Flores, et al., 2002). Despite the growing number of Latino children, there is a dearth of empirical research on specific mental health problems experienced by this burgeoning population. Lack of education regarding childhood mental illness and limited access to services are suspected to contribute to underreporting and, in turn, lack of treatment among Latino children. For example, studies have demonstrated that White children are more than twice as likely to receive diagnosis and treatment of Attention Deficit Hyperactivity Disorder (ADHD) than African American and Latino children (Olfson, Gameroff, Marcus, et al., 2003; Eiraldi, Mazzuca, Clarke, et al., 2006). In addition, despite problems with surveillance of Latino childhood mental health problems, a study by Canino, Could, Prupis, and Shaffer (1986) indicated that Latino children are at greater risk for depression, anxiety, school refusal, and difficult interpersonal relationships with other children than their Black or White counterparts.

The disproportionate mental health disease burden among Latino children is especially troubling given the negative health outcomes that result from childhood mental health disorders (Flores, et al., 2002). Childhood is a crucial period in the lifecycle, marked by rapid changes in cognitive and emotional development; mental health disorders can cause academic and social impairment, which have serious ramifications on the developmental trajectories of children later in life. For example, research has demonstrated that early-onset emotional and behavioral problems in children are related to negative consequences in adolescence, such as educational difficulties (Tuakli-Williams & Carillo, 1995), substance use (Sterling, Kohn, Lu, & Weisner, 2004), juvenile delinquency and school dropout (Loeber, 1991; Ramey, & Ramey, 1998), and attempted suicide (CDC, 1999).

### Risk Factors for Latino Children's Mental Health Problems

While it is clear that additional research must be conducted in order to determine base rates of mental illness among Latino children, a significant body of literature exists documenting risk factors that may lead to or exacerbate mental health disorders among Latino youth. Twenty-eight of Latino families reside in poor families (NCCP, 2005), and Latino children are more likely to live in resource poor, urban neighborhoods than their White counterparts (Kasarda, 1993; Fass & Cauthen, 2006). These children are often exposed to negative environmental stressors, such as overcrowding, neighborhood disorder, community violence, and trauma exposure, factors which have been linked to childhood psychopathology (Wandersman & Nation, 1998; Vostanis, Tschler, Cumella, et al., 2001; McKay, Lynn, & Bannon, 2005). A study by Xue, Leventhal, Brooks-Gunn, et al.(2005) demonstrated that children in neighborhoods of low socioeconomic status have the highest levels of mental health problems when compared to children in medium and high socioeconomic status neighborhoods. Low social control, lack of community cohesion, and compromised social capital networks have all been linked to negative mental health outcomes in children (O'Brien, O'Campo, & Muntaner, 2003; Xue, et al., 2005).

Two other crucial factors that may contribute to the development of childhood mental health disorders among Latinos are acculturation and adjustment stress. Recent data from the Mexican American Prevalence and Services Survey indicated a positive association between acculturation and risk for lifetime prevalence of diagnosable mental disorders, such as affective,

anxiety, and substance use disorders (Organista, Manoleas, & Herrera, 2001). Latinos who emigrate to the U.S. often experience difficulties maintaining their traditional cultural norms while attempting to integrate North American cultural practices and beliefs (Sue & Sue, 2003). While some Latino children are able to navigate the acculturation process smoothly and establish a bicultural identity, which has been shown to be the most beneficial resolution to acculturation conflicts for the individual (Miranda & Umhoefer, 1998), other Latino children often find themselves caught between expectations of their family and their school or peer groups (Flores-Gonzalez, 2002). These types of acculturation conflicts can cause significant psychosocial adjustment stress, which may lead to the development of mental health problems.

### Latino Children's Access to Mental Health Care

Despite the greater need for mental health services among Latino populations, there is evidence that the majority of these children are not receiving necessary care. Recent studies by Kataoka, Zhang, and Wells (2002) and Zimmerman (2005) revealed that Latino children have especially high rates of unmet need in terms of mental health service delivery relative to other children. This difficulty accessing mental health services can be attributed to three primary factors: (1) insufficient services, (2) health insurance barriers, and (3) cultural barriers.

#### *Insufficient Services*

The U.S. currently faces a dramatic shortage of mental health providers who are specifically trained in the provision of mental health services to children and adolescents (Kim, 2003). A recent study by Thomas and Holzer (2006) indicated that youth living in poverty were least likely to have access to specialty child psychiatry services. These findings are especially salient for Latino families, 28% of which are living below the federal poverty line (NCCP, 2005). A study conducted by Lopez (2002) cited availability of services as one of the many barriers to accessing mental health care among Latino families. In addition, many Latino families lack information regarding mental health services and recognition of child mental health problems (Teagle, 2002). Thus, Latino parents may not have the knowledge necessary to obtain appropriate mental health services for their children even when such services do exist.

Furthermore, some Latino families may have difficulty seeking mental health treatment due to immigration status. A study by Granados and



colleagues (2001) demonstrated that Latino children of immigrant parents were less likely to access routine healthcare than Latino children of U.S. born parents. While more research must be conducted to determine specific reasons why children of immigrant parents seem to have more difficulty accessing healthcare services, one possible explanation is that these parents may fear that they will be questioned about their immigration status when seeking care for their children. Research conducted by Canlas (1999), which examined mistrust of the health care system among Latinos in East Harlem, New York, found that fear of deportation was a major reason given for underutilization of medical services by Latino participants. As such, undocumented Latino parents may be afraid to inquire about mental health services for their children, for fear they may be questioned about their immigration status, harassed or deported.

### *Health Insurance Barriers*

Other factors impacting Latino children's ability to access mental health services revolve around health insurance. Approximately 26% of Latino children are uninsured, compared with 10% of White children and 14% of African American children (Flores & Vega, 1998). While significant improvements have been made in health insurance for minority children over the past 30 years, such as the expansion of Medicaid eligibility and the introduction of the State Children's Health Insurance Program (SCHIP), insurance status continues to present a significant barrier to Latino families' ability to access mental health services (Alegría, Canino, Ríos, et al., 2002; Busch & McCue Horwitz, 2004). Medicaid and private insurance benefits are often administered through managed care organizations. While this arrangement has conserved a considerable amount of government money, significant questions arise regarding pre-certification for mental health services, disenrollment, and quality of care provided to minority children with mental illness.

In addition to ineffective diagnostic and referral systems, managed care's confusing guidelines also complicate coordination efforts between mental health providers, families, and schools. Children with mental health problems are often treated by many different systems and agencies, including schools, social services, and the juvenile justice system. Lack of coordination and failed communication (many times resulting from language barriers) among teachers, social workers, and the courts often lead to inconsistent care for Latino children. In some cases there may be an overlap in services, where children and families receive confusing messages from multiple sources. However, more commonly, due to large caseloads and reduced funding, children

fall between the cracks as the various agencies try to pass off costs to other sectors. This is evidenced by the fact that 92% of children with serious emotional disturbances receive mental health services from two or more systems, and 19% from four or more (Glieb & Cuellar, 2003).

### *Cultural Barriers*

Latino communities face significant cultural obstacles to obtaining mental health care. Research suggests that Latino families often do not view mental illness as a medical problem; instead some Latino families conceptualize mental illness as a spiritual or religious issue (Maduro, 1983; Sue & Sue, 2003). As a result, Latinos tend to underutilize mental health services while relying heavily on religious services for the resolution of emotional and interpersonal disturbances (Organista, Manoleas, & Herrera, 2001). While churches and other religious organizations may be a useful source of psychosocial support for Latino families, staff is seldom trained in the recognition of mental health disorders, which may lead to underreporting of mental health disorders and in many cases insufficient treatment of Latino children with mental health disorders.

Insufficient research has been conducted on the impact of culture and language on the etiology of mental health disorders and the underutilization of mental health services among Latino children (Flores, et al., 2002). For example, few studies have examined the ways in which cultural constructs specific to Latino populations may impact the way in which mental health is viewed and treated in Latino communities. A shortage of bilingual and bicultural mental health providers further impedes access to effective mental health services for Latino children (Vega & Lopez, 2001). As a result, if Latino children are receiving mental health services, these services may be culturally irrelevant and ineffective, leading to premature discontinuation of treatment. Some critics of the U.S. mental health system assert that the dearth of bicultural mental health professionals is representative of a form of aversive institutional racism that may make it difficult for Latino families to participate in treatment altogether (Whaley, 1998).

## Latino Children's Mental Health Service Delivery

### *Micro-level Interventions: Individual & Family*

The majority of intervention programs that address Latino children's mental health on the micro level have been carried out within family systems.

Children's ability to access health care services almost always relies on their parents' willingness to seek out and/or accept these services (Newacheck, Hughes, Hung, et al., 2000). Unfortunately, Latino parents may not realize that their children may be experiencing a serious mental health problem. For example, a recent study that sought to measure parental problem recognition and its impact on child mental health service use, determined that parental perceptions of their children's mental illness played a key role in determining whether or not their children were able to receive services (Teagle, 2002). Education at the parental level is crucial to the identification of serious mental health problems.

A handful of empirically tested intervention programs specifically tailored for Latino populations have helped to educate Latino parents on normal childhood development and train parents to identify abnormal child behavior. For example, culturally adapted parent management training was designed by the Oregon Social Learning Center to educate parents on mental illness and help parents acquire general parenting skills in order to decrease externalizing behaviors in their adolescent children (Martinez & Eddy, 2005). This intervention proved successful in reducing a range of adolescent problem behaviors, including aggression and drug use. The strength of this program was its specificity; all parent-adolescent dyads studied were Spanish-speaking and parents were encouraged to express their own views of normal vs. abnormal child behavior based on previous experiences.

### *Mezzo-level Interventions: School & Community*

School-based interventions are perhaps the most widespread programs to address mental health problems among Latino children. Schools are a logical place for the identification of child mental health problems because the vast majority of children attend school and can be closely monitored by teachers and ancillary mental health staff (Hoagwood, Burns, Kiser, et al., 2001). One of the primary strengths of school-based programs is their ability to provide consistent support to children struggling with mental health problems. In 1999, Ambruster and Lichtman conducted a study to evaluate the effectiveness of 36 school-based mental health services in inner city New Haven, Connecticut. This study demonstrated that children enrolled in school-based mental health services showed comparable improvement in functioning on the Children's Global Assessment Scale and the Global Assessment of Functioning Scale to children enrolled in clinic-based mental health care. This study also highlighted the crucial role that schools can play in mental health problem

identification and treatment because they are able to reach disadvantaged children who otherwise would not have access to mental health services. School-based mental health services can be highly affective at improving academic achievement in high-poverty urban areas (Atkins, Frazier, Birman, et al., 2006) and are able to coordinate treatment planning with teachers and administrators, which allows for the development of educational plans that are informed by mental health treatment and vice-versa.

Community-based interventions that address mental health treatment are also widespread (Hoagwood, et al., 2001). These interventions most often take place in community outpatient mental health centers or through integrated treatment coordinated through case management services at community-based organizations. While these settings are particularly effective in addressing mental health problems among children due to the presence of more skilled providers and psychiatrists who are able to prescribe medication, the weaknesses of community-based interventions lies in their inability to reach many Latino children. As previously mentioned, structural barriers, such as availability of services and insurance restrictions inhibit Latino children's access to mental health services (Flores, et al., 2002). Furthermore, cultural barriers to treatment, such as lack of Spanish-speaking and/or bicultural providers, even in communities where the majority of children come from Latino backgrounds, often prevent Latino families from utilizing community outpatient services (Vega & Lopez, 2001).

### *Macro-Level Interventions: Structural Transformation and Policy Development*

Policies to improve insurance coverage for low-income children, such as Medicaid expansion and the formulation of SCHIP, are examples of structural level interventions that have helped to alleviate the mental health disease burden in Latino children (Shone, Dick, Crach, et al., 2003). Another example of structural level change resulting in improved access to mental health services for Latino children is the Mental Health Parity Act, which took effect in 1996. This act, which was an important step in acknowledging the importance of mental health and placing it on an equal plane with physical health, ensured that mental health care benefit limits were comparable to all other benefits (Sturm & McCulloch, 1998). This change was accompanied by the development of many new pharmaceuticals to treat mental health problems, and increased prescription benefits. As a result, insurance companies now cover mood stabilizers and psychotropic medications in the same way other medications

are covered, which has further equalized the mental and physical health sectors while reducing costs to patients.

Two other examples of macro-level interventions that have helped improve mental health among Latino children are Head Start and Early Head Start, two Federal programs within the Administration on Children, Youth and Families in the Department of Health and Human Services. These programs offer comprehensive services aimed at improving the physical and emotional well-being of pre-school children in low-income families (ACYF, 2007). Head Start programs have been effective in promoting mental health among participants by working closely with parents to identify mental health problems in the family system and work with children and parents to address these concerns (Mann, 1997). While Head Start and the other structural level interventions mentioned above were not specifically aimed at improving the mental health of Latino children, such far-reaching policy implementation has been crucial to the improvement of Latino children's mental health due to its ability to affect systemic change.

### Recommendations

#### *Micro-level Interventions: Individual & Family*

Mental health disorder identification in children can be most effective if it occurs early (DHHS, 2000). Future intervention programs aimed at Latino families must target parents of younger children in order to help them recognize abnormal behaviors and seek appropriate care. In addition, all individual and family level interventions targeting Latinos must be culturally tailored to the specific Latino subgroup being targeted. There is a tendency in social work and public health research to group all Latino populations under the umbrella terms "Latino" or "Hispanic," without paying attention to specific differences between subgroups based on country of origin (Flores, et al., 2002). This is problematic in that it fails to recognize the unique social and historical differences between Latino subgroups, including acculturation and other factors which may speak directly to child development and mental illness. While emerging research in the field of mental health has begun to examine Latino subgroup differences, this is another area for the improvement of intervention strategies on the individual level. Mental health problem intervention programs must be tested with specific Latino subgroup populations in order to determine efficacy and inform further specificity.

Clinicians who work with Latino youth must also make themselves aware of the unique social and cultural issues affecting this population and the ways in which these factors may impact clinical work on the individual level. As previously mentioned, Latino youth are disproportionately affected by a number of psychosocial stressors, including the deleterious effects of poverty, institutional racism, and community violence. In preparing to work with Latino children, social workers must make a thorough assessment of the context in which the client lives, as well as individual functioning. Parental involvement is crucial to any intervention aimed at children (McKay, Pennington, Lynne, et al., 2001). Recent research has demonstrated that family support and family cultural conflict were strongly associated with self-rated mental health among Latinos (Mulvaney-Day, Alegria, & Sribney, 2007). Therefore, it is essential that social workers treating Latino children engage parents and other family members in their efforts to help the child achieve greater psychosocial functioning.

### *Mezzo-level Interventions: School & Community*

In order to improve school and community-based services, a number of steps could be taken. First, schools and community-based clinics could begin funding and implementing social marketing campaigns to educate children, parents, and community members about mental health problems. Social marketing campaigns can have small-to-moderate effects on health knowledge, beliefs, attitudes, and behaviors, which can be translated into significant, positive public health outcomes (Noar, 2006). Community mental health intervention programs with a strong social marketing component have been used in Australia with favorable results (Wright, McGorry, Harris, et al., 2006); similar programs that specifically target Latino children's mental health in the U.S. may also be effective. Through culturally tailored materials and targeted outreach efforts in English and Spanish, schools and community-based clinics may educate Latino families on the early detection of childhood mental health problems, inform parents of where to take their children for mental health screenings, and help to reduce the often conflicting information regarding etiology and treatment of mental illness in Latino communities.

Service providers, especially teachers and pediatricians that work with Latino families, may also be targeted on a community level. These professionals are often encumbered by limitations in implementing preventative services. For example, teachers are often assigned large class sizes and primary care

physicians are required to see more patients in less time. As a result, these professionals have less time to develop strong, ongoing relationships with families and are less likely to identify mental health problems (AAP, 2000). While the American Academy of Pediatrics recommended increased funding for specialized training programs and job incentives for qualified child mental health clinicians in 2000, the U.S. continues to lack sufficient numbers of trained mental health workers to handle the specific mental health care needs of Latino children. In order to address this problem, school- and community-based interventions may offer teachers and pediatricians extensive training on the recognition of mental health problems in children. By educating these providers about the importance of mental health screening, school- and community-based programs can expand the network of competent providers evaluating Latino children for mental health problems.

*Macro-Level Interventions: Structural Transformation and Policy Development*

Despite the success of existing policy-level interventions, much more can be done to improve Latino children's mental health on a structural level. For example, one of the key problems with mental health service delivery to Latino children is the severe shortage in culturally competent, bilingual service providers. Without Spanish-speaking mental health professionals who are able to understand and address the unique cultural considerations surrounding mental illness in Latino communities in clients' preferred language, Latino children will continue to be underserved by the mental healthcare system. Local, state, and federal governments must be involved in efforts to expand minority provider networks. This may be done through the implementation of scholarship programs for Latinos interested in mental healthcare and/or tuition payback programs for providers who learn Spanish, participate in cultural competency trainings and work in minority neighborhoods after graduation. These types of programs currently exist but they are often financed by private foundations. City, state, and federal policymakers may expand such programs by drafting legislation that institutionalizes and funds tuition payback programs in order to improve Latino children's mental health in a more widespread manner.

Policymakers can also improve mental health services for Latino children by implementing monitoring systems for mental health service provision and economic penalization for substandard service. "Families need mechanisms to communicate their comments and experiences [regarding mental health services] to those who purchase health care plans" (AAP, 2000, p. 862). In turn, healthcare purchasers must be responsible for providing adequate

information to clients about the quality and availability of culturally relevant mental health services. Many Latino children receive mental health services through federal programs, such as Medicaid and SCHIP. By setting up feedback systems that allow parents to express dissatisfaction with the quality of care their children are receiving, policymakers will help clients have a voice in the type of care they are offered. Opening channels for criticism, and backing up criticism with economic ramifications, will encourage mental health care providers to increase levels of service to meet clients' needs.

State and federal level policies can also help improve the detection and prevention of mental health problems among Latino children by implementing mandatory mental health screening programs in public schools. One of the main reasons for disparity in the need for mental health services and service provision is missed opportunities for early intervention. While time, energy, and financial resources have been devoted to programs promoting children's physical health, little emphasis has been placed on mental health among children. U.S. children are required to have physical examinations in order to attend public school; however, psychological evaluations are usually reserved until social, behavioral, or cognitive problems are far advanced. Government policies to implement mandatory screening for mental health problems in public schools will ensure the early detection of Latino children's mental health problems. However, in order for screening programs to be effective, they must be reinforced by comprehensive services to treat Latino children's mental health problems.

## Conclusion

Latino children are at heightened risk for developing mental health problems due to a range of psychosocial factors, including poverty, community violence, acculturation, and adjustment stress (Wandersman & Nation, 1998; Vostanis, Tschler, Cumella, et al., 2001; McKay, Lynn, & Bannon, 2006). At the same time, these children often face significant barriers to receiving mental health services resulting from limited education regarding mental illness, scarcity of bilingual and bicultural service providers, and aversion to the mental health system due to cultural, spiritual, and religious factors. While some intervention programs have been implemented at the individual, community, and structural levels to address Latino children's mental health, much remains to be done in order to address this significant public health concern.



Improvement of education campaigns targeted at parents and primary healthcare providers, expansion of community-based programs to address the limited knowledge surrounding mental illness and the scarcity of appropriate service providers, and implementation of policies for early screening, detection, and treatment are just a few of the strategies that may be employed to reduce the negative outcomes resulting from mental health problems in Latino children. In order for these changes to take place, mental health practitioners must view Latino children's mental health as a priority and engage in advocacy efforts at all levels of social work and public health practice.

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*In families affected by domestic violence, women are typically both the battered party and the parent most likely to be responsible for the caretaking of children. Although the domestic violence and child welfare service systems both work towards ending family violence, conflicting goals reflect the historical tension between the woman-centered battered women's movement and the child-centered child welfare system. This article considers the overlap between the domestic violence and child welfare service systems and women's place at the intersection of these two spheres. Suggestions to improve policy and practice are made for social workers who serve battered women and children affected by family violence.*

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The overlap of domestic violence and child maltreatment is well established, with numerous studies showing that child abuse and partner abuse are often co-occurring forms of family violence (Edleson, 1999a). Less recognized, however, is the disproportionate burden women bear at the intersection of the child welfare system and battered women's services. Domestic violence (also called intimate partner violence) most frequently describes violence perpetrated by men against their female partners and ex-partners (Humphreys, 1999). As typically both the battered party and the primary caregiver (Maxwell, 2000), a mother in a family affected by domestic violence is often subject to the competing demands for keeping herself and her child safe. Surprisingly, given the rates of co-occurrence and populations served, the child welfare system and battered women's movement often operate in different spheres, emphasizing different values and philosophies. Although both are designed to protect women and children, the two systems at times work at cross-purposes, an opposition that further victimizes women. New policy and practice methods should consider the intersection of these two systems and develop ways to support women and children from a strengths-based, holistic perspective that does not ignore the gendered dynamic of both systems.

The number of children exposed to domestic violence each year is estimated at 3-10 million, and studies suggest that there are both child and adult victims in 30 to 60% of families affected by domestic violence (U.S. DHHS, 2003). Studies show that the long-term effects of domestic violence on children have serious implications on child development and well-being. Children who witness domestic violence are more likely to exhibit signs of social, cognitive, emotional and behavioral problems, and are at increased risk of drug abuse, suicide, and homelessness (Park, et al., 2004; Edleson, 1999b; Onyskiw, 2002; National Coalition Against Domestic Violence, 2005).

Despite progressive policies designed to differentiate between children witnessing and experiencing direct abuse, current child welfare practice often removes children from households with a recent history of domestic violence. If the child welfare system becomes involved with a family affected by domestic violence, women may be compelled to make difficult choices about housing, work arrangements, childcare, and child custody. For instance, a battered woman, by leaving her abuser and taking her children with her to live in a shelter or on the streets, may risk removal of her children by the foster care system because of a lack of appropriate housing options (Pearce, 1999). Predictably, many women choose to deny the presence of domestic violence in order to avoid its social and legal ramifications and to prevent the removal of her children into the foster care system.

### Different Perspectives on Protecting Battered Women and Their Children

Child advocates and battered women advocates alike acknowledge the historical tension between their philosophies as reflected by the child-centered child welfare system and the woman-centered battered women's movement (Beeman, Hagemester, & Edleson, 1999). Although the two systems both work towards ending family violence, their goals are sometimes in conflict. Battered women's advocates criticize the child welfare system for turning a blind eye to domestic violence (Pennell & Burford, 2000) or, when the presence of domestic violence is evident, holding the woman and not the batterer responsible for the safety and well-being of the child (Saunders & Anderson, 2000). While some domestic violence service providers acknowledge the co-occurrence of abuse of women and children, many still view women as the primary victims and children as secondary victims (Pearce, 1999).



Grounded in a feminist perspective, some domestic violence service providers argue that empowering women ultimately benefits children and choose to serve women first and their children collaterally. Children's advocates hold that children have their own needs that are not always met by serving their mothers first or exclusively.

The differences between the two systems are echoed even in their outcome goals. Child welfare policy, along with the permanency planning required by the Adoption and Safe Families Act of 1997 (ASFA), uses practice language such as "family preservation" and "family reunification" (Pennell & Burford, 2000). On the other hand, the battered women's movement considers options for women that separate her from the batterer, whether psychologically (individual counseling), legally (via protective orders or divorce proceedings), or physically (alternative housing).

### Battered Women in the Child Welfare System

A societal bias which views women as primarily responsible for the care of their children is reflected in the child welfare system. Socially and legally, women more often than men are blamed for the poor treatment of their children and are more harshly judged when their children are maltreated, regardless of who commits the maltreatment (Saunders & Anderson, 2000). While the legal and child welfare systems penalize women for failing to protect their children, these same systems are often criticized for neglecting to pursue punishment of or interventions for the batterer, instead focusing on what the mother's responsibilities are for keeping her child safe (Edleson, 1999a). As one study found, "women are held responsible for both their male partners' behavior and the protection of their children" (Pearce, 1999, p. 112). Another study of child protection workers and battered women's advocates found that Child Protective Service (CPS) workers rarely included the male perpetrator of violence in family service plans (Beeman, Hagemeister, & Eldeson, 1999).

Although ASFA emphasizes adoption and permanency planning, which critics of the act contend interferes with family preservation efforts, procedures remain for removing children when doing so is deemed to be in the child's best interest or in order to keep the child safe (Postmus & Ortega, 2005; Saunders & Anderson, 2000). In some cases, if a woman does not leave her abuser, caseworkers may perceive a betrayal of a mother's inherent responsibility to protect her children and may hold the woman responsible for the abuse by removing the child from her care (Magen, 1999).



Women's advocates believe that removing a child from a mother's care is a second victimization, punishing the mother for her batterer's actions (Beeman, et al., 1999). A landmark New York court case, *Nicholson v. Scopetta*, 344 F.3d 154, 164 (2d Cir. 2003), alleged that the Administration for Children's Services was unduly removing New York City children, who were not otherwise abused, from their families in which domestic violence was taking place and charging their mothers with neglect (Postmus & Ortega, 2005). The court found that such practice was illegal and, in effect, penalized mothers for being battered. Not all states, however, have such a legal precedence and some child welfare practices continue to punish women for their batterer's abuse by placing their children into foster care. In fact, the law in this area of child as domestic violence witness continues to develop and carries important implications for women including potential legal responsibilities and consequences.

### Children's Exposure to Domestic Violence

Battered women are repeatedly confronted with untenable choices. Some women feel emotionally trapped, physically threatened, financially constrained, and/or psychologically tethered to their batterer. Domestic violence advocates recognize the complexity of these choices and provide services that look to empower and support women. The effects of domestic violence on children, however, are not as well understood, and children's needs are often subjugated by legal systems that respond to adult demands. In some cases, children are witness to, but not the direct targets of, intimate partner violence. In other cases, children are hurt as bystanders. Research shows, however, a significant number of battered women's children have also been physically or sexually abused themselves (Humphreys, 1999), and the abuse may be perpetrated by any primary caretaker, whether male or female.

Edleson (1999b) found that children of battered women can experience a tangle of emotions as a result of their experiences and are not receiving the services they need to address these complicated psychosocial needs. For instance, children of battered women, in addition to coping with the effects of being witness or subject to violence, may be also struggling with having to move out of their home, separate from a parent and/or other family members, change schools, and reconcile their love for the batterer with their sense of betrayal. Child-centered advocates in the movement against domestic violence contend that children have needs that are not always addressed by protecting and empowering women (Beeman et al., 1999). Viewing children as individuals

with agency, they argue, demands that service systems be restructured to assess and address children's specific needs and not just those that derive from their mother.

### Current Practice Methods

The lack of coordination between the child welfare system and battered women's movement reveals numerous missed opportunities to serve both women and children. For instance, New York state law does not require that CPS be notified in domestic violence cases (Bent-Goodley, 2004) despite the fact that CPS workers called to intervene in an at-risk family are in an excellent position to recommend or make referrals to domestic violence services. In fact, a study of battered women served by a New York City child welfare preventative service agency found that battered women want child welfare workers to ask them about current and past incidents of domestic violence (Magen, et al., 2000) so that appropriate services can be implemented. Additionally, women's shelters, the populations of which are primarily children, are a unique opportunity to provide children with counseling and other therapeutic services, which are not routinely in place (Magen, et al., 2000).

Studies have found that caseworker perception of domestic violence plays a large role in the services rendered to family members affected by the violence (Yoshihama & Mills, 2003; Postmus & Ortega, 2005). Consequently, understanding caseworker attitudes towards domestic violence is important to developing sensitive and effective interventions that protect both women and children. For example, Humphreys (1999) found that some child caseworkers believe that their guiding mandate is the best interests of the child and do not always perceive themselves to be advocates for battered women. In other cases, studies show that some child welfare workers blame the mother for failing to protect her child by remaining in the abusive household or maintaining a relationship with her batterer (Petrucci & Mills, 2002; Saunders & Anderson, 2000). To the contrary, evidence suggests that many women stay in abusive relationships in order to protect their children from potential abuse from the batterer (Schechter, & Edleson, n.d.).

Maxwell (2000) argued that corollary institutions serving battered women and their children, such as the courts and welfare programs, also need improved coordination. Women receiving welfare assistance may find that they are given competing advice from welfare and child welfare officials about, for instance, work requirements that conflict with the responsibilities a mother has to keeping

her children safe at home (Pearce, 1999). More research is needed to explore the interaction between related services that support battered women, including substance abuse services, social welfare programs, and the criminal and civil court systems, so that the provision of services is not in conflict.

### Implications for Domestic Violence and Child Welfare Practice

Numerous studies point to the efficacy of educating child welfare caseworkers on domestic violence. Education and training programs have been found to be successful in changing child caseworker attitudes and in using assessments and interventions in domestic violence situations that do not further victimize women (Postmus & Ortega, 2005; Magen, et al., 2000; Saunders & Anderson, 2000). Petrucci & Mills (2002) study found that although most states have some procedures in place that integrate questions about domestic violence into child abuse risk assessment forms, most standardized instruments that screen for domestic violence do so only insofar as the violence affects the child. Additionally, battered women's advocacy organizations might benefit from training that highlights the need for child-centered assessments and interventions that do not ignore the specific effects of domestic violence on children.

Battered women may benefit from culturally-relevant education programs that address both the effects of family violence on children and resource availability (Schechter & Edleson, n.d.). Parenting classes, a standard part of family service plans instituted by child protection agencies, can assist women in developing a clear safety plan in a way that empowers women to direct their own choices. At the same time, family service plans should not ignore the batterer's responsibility to the plan if safe and appropriate (Schechter & Edleson, n.d.). Some battered women may be coping with feelings of guilt as a result of her perceived failure to protect her child from violence or from her child's removal into the foster care system. Other women, who feel powerless against her abuser, may see her role as a mother as one area over which she still has some control and pride. Effective parenting classes should be sensitive to such considerations by using a strengths-based perspective that is empowering to women.

To supplement caseworker training, implementing concrete protocols can help mitigate the effects of workers' own feelings about domestic violence on child abuse assessment and intervention. Other institutional changes include hiring domestic violence specialists at child welfare agencies (Saunders & Anderson, 2000). Additional promising practices include family group

conferencing, an intervention that brings together all members of the family affected by the abuse who collaboratively construct a plan to stop the maltreatment and keep all family members safe (Pennell & Burford, 2000). Finally, additional research is needed to explore the differential effects of race, culture, and ethnicity on child welfare assessments of family violence so that interventions and services are culturally competent.

## Conclusion

Battered mothers negotiate the dual role of primary caretaker to their children and abuse victim, balancing at the fulcrum of two social service systems: family violence and child protection. New policy and practice methods that marry the efforts of child advocates and battered women's advocates support the idea that protecting women and children is not a zero-sum affair. Rather, it requires coordination on the part of multiple social service systems and a reframing of historically held philosophies that privilege the safety of either women or children over the other. Child welfare training should be sensitive to the complicated position of battered women, while the battered women's movement should resist considering children as secondary victims of domestic violence. Social workers at the confluence of these systems are in a unique position to assist battered women in creating a safety plan that addresses the woman's needs as well as the needs of her children. Through collaboration, women-centered and child-centered approaches can minimize the bias of the "failure to protect" clauses against mothers, hold batterers accountable, and help domestic violence survivors keep their children safe.

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*Women with families are the most quickly increasing segment of the homeless population. Varying from state to state, between 22% and 85% of these homeless families report that they became homeless as a result of the choice to flee an abusive relationship. Domestic violence survivors are at risk of homelessness before entrance into the emergency shelter system, before gaining acceptance into the transitional shelter system, and once they have secured low-income housing. This problem has resulted in many domestic violence survivors choosing to remain with their children in violent homes as opposed to becoming homeless. Obstacles to help-seeking and limitations of emergency housing options are current issues resulting in homelessness among domestic violence survivors. Programmatic and policy recommendations are made to assist domestic violence survivors in obtaining and maintaining both long and short term housing.*

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Women with families fastest growing segment of the homeless population (Menard, 2001). The majority of large cities in the United States identify domestic violence as a primary cause of homelessness for families (Correia & Rubin, 2001). Social service providers commonly work with women who are simultaneously homeless and in need of domestic violence-specific services. Domestic violence survivors are often forced to choose between homelessness and continued abuse. Varying from state to state, between 22% and 85% of homeless families report that they have become homeless as a result of leaving a home in which abuse has occurred (Bufkin & Bray, 1998). Conversely, 46% of homeless women surveyed in 2003 reported staying in an abusive relationship in the past as an alternative to becoming homeless (Wilder Research Center, 2004). Neither option is ideal.

This paper will address the factors that contribute to homelessness among domestic violence survivors and the systematic responses that are intended to provide both short and long term housing. Unfortunately, there is a lack of research conducted on this phenomenon and a formal assessment of the problem or of the effectiveness of available housing options has not been performed. The paper will conclude with recommendations for future

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research, programs, and policies based on the literature review.

## Factors Contributing to Homelessness

Many domestic violence survivors feel as though they have no choice but to flee to confidential emergency domestic violence shelters when the formal systems in place to support them fail (Bufkin & Bray, 1998; Correia & Rubin, 2001). They face barriers to employment, ineffective law enforcement and limited permanent housing options, thereby leading domestic violence survivors to make the choice to leave their partners and enter the shelter system.

### *Barriers to Employment*

Finding and maintaining employment is a significant challenge for domestic violence survivors due to various actions conducted by their abusive partners. A survey of 285 women found that domestic violence survivors are more likely to be stalked at the workplace, have work materials destroyed by their partner, be prevented from leaving the house, or murdered by their partners at work. These factors contribute to the inability of surveyed domestic violence survivors to maintain employment for six months or more (Browne, et al., 1999). Furthermore, abusers often destroy domestic violence survivors' credit histories and leave the survivors with negative landlord references as a result of their disruptive and/or destructive behavior (Correia & Rubin, 2001; Melbin, Sullivan & Cain, 2003). Inability to maintain employment and the resulting lack of income forces domestic violence survivors to seek free, alternative housing as opposed to obtaining temporary private housing, such as a hotel or apartment (Williams, 1998).

### *Challenges in the Criminal Justice System*

Criminal Justice system responses may exacerbate the victimization of domestic violence survivors due to insufficient training and education of criminal justice professionals and failed enforcement of orders of protection. Bufkin and Bray (1998) suggest that most people involved in law enforcement (police officers, judges, attorneys, and jurors) rarely receive education as to the seriousness of domestic violence assaults. If police are called and an arrest is made, the abuser is generally held for only a short period of time and can return home when released (Bufkin & Bray, 1998). Enforcement of orders of protection is dependent upon availability of police and their willingness to take action. Since law enforcement officials do not make domestic violence



calls a priority, research has shown that orders of protection do not increase the likelihood of arrest (Bufkin & Bray, 1998). Due to the inadequacy of this formal support system, domestic violence survivors are often forced to seek safety in a secure, confidential location, such as a domestic violence shelter.

Low-income domestic violence survivors face additional housing risks when deciding whether or not to involve law enforcement officials in abuse. Many women are eligible for low-income housing as a result of their status as a single, unmarried parent. If another person is found to be living with them without the permission of the housing authorities, they are at risk of being evicted. Many domestic violence survivors who are in this situation are therefore reluctant to report instances of domestic violence to law enforcement for fear of losing housing. Aware of this risk, some abusers gain control by threatening to tell the housing authorities (Raphael, 2001).

### *Lack of Affordable Housing*

Women are disproportionately affected by housing barriers unrelated to domestic violence, such as “a decrease in the number of affordable housing units nationwide, a decline in federal funding for low-income housing, and the skyrocketing costs of low-income housing coupled with low wages” (Correia & Rubin, 2001). Between 2004 and 2006, funding for the United States Department of Housing and Urban Development (HUD), the umbrella under which Section 8 falls, decreased by 8% or \$3.3 billion. Additional cut-backs of \$1.3 billion have been proposed for 2007 (Rice & Sard, 2007). As a result of these barriers, domestic violence survivors have an increased likelihood of being evicted due to an inability to pay rent. Domestic violence survivors report the inability to pay bills on time, and often face having to decide between buying food and paying rent. Eviction can also be the result of property damage caused by abusers through violence toward their partners or deliberate property destruction (Baker, et al., 2003).

Prior to the passage of the Housing Opportunity Program Extension Act of 1996, domestic violence survivors were considered a “special needs population” and were given preference in federal housing assistance (Correia & Rubin, 2001). In addition to eliminating this preference, this act increases the likelihood of eviction for domestic violence survivors by implementing a “one strike policy” in which housing authorities can “deny housing based on past criminal activity” and create a “zero tolerance policy” (Correia & Rubin, 2001). Often domestic violence survivors are forced to engage in self defense in response to an act of violence. The “zero tolerance policy” does not

distinguish between the actions of domestic violence survivors and perpetrators, potentially resulting in the eviction of the survivor and her family (Correia & Rubin, 2001).

When seeking housing after leaving an abusive partner, women frequently face discrimination by landlords. Currently there is no legislation to prevent against housing discrimination on the basis of being a domestic violence survivor; therefore discrimination is common-place. For example, the Anti-Discrimination Center (2004) made phone calls to 40 housing providers; when the prospective tenant was described to the landlord as a survivor of domestic abuse, 27.5% either “refused to rent” or “failed to follow up.” In another 20% of cases, housing providers made stereotypical comments and asked questions to obtain information about the mental status of the survivor and the ability of the abuser to cause harm to the survivor, other tenants, and building staff. This example illustrates the stigmatization domestic violence survivors often confront when attempting to secure permanent housing.

### Current Responses

There are various short and long term interventions available for domestic violence survivors who are in need of housing. However, they often fail to meet the needs of this population. Upon the initial decision to flee, domestic violence survivors encounter numerous obstacles in gaining acceptance into shelter. Many homeless shelters do not consider domestic violence survivors to be homeless in the traditional sense, as they “chose” to leave their homes (Williams, 1998). Therefore, they must focus on attaining beds at limited emergency domestic violence shelters where undocumented, pregnant, disabled, or women with teenaged male children can rarely gain acceptance (Voices of Women Organizing Project, 2005).

### *Emergency Shelters*

The emergency shelter system can be divided into two types of shelters: domestic violence-specific shelters and homeless shelters. A 2006 study conducted by Stainbrook and Hornik compared the similarities and differences in domestic violence shelters and homeless family shelters in three counties in New York State. They found that both types of shelters provide case management in the form of housing assistance and financial management skill-building. However, the domestic violence shelters provide more domestic violence-specific services, which include: legal assistance, parenting skills training,

counseling, and self-help and support groups (Stainbrook & Hornik, 2006). This emphasis on therapeutic support results in women scrambling at the ends of their stays to find housing and often returning to their batterers in the attempt to avoid homelessness. Homeless shelters are more focused on helping residents secure permanent housing and allow them more time to do so than emergency domestic violence shelters. However, homeless shelters do not guarantee confidentiality or protection, placing many women and their children at risk of attack (Williams, 2003).

### *Transitional Shelters*

After leaving an emergency domestic violence shelter, a small percentage of domestic violence survivors are accepted into transitional shelters. These shelters grant their clientele more independence by allowing them to seek employment and by providing them with longer-term shelter of approximately 1-2 years (Melbin, Sullivan, & Cain, 2003). While transitional shelters provide a bridge between shelter and permanent housing, there are a limited number of such shelters. Further, staff members at such programs are likely to select “model” applicants who can easily become financially independent as opposed to applicants who may have many children, or who may be dealing with emotional distress, substance abuse, and/or struggling to gain employment (Melbin, Sullivan, & Cain). The average applicant coming from an emergency domestic violence shelter is left without the option of transitional housing and at risk for homelessness.

### *Long-Term Housing*

After leaving emergency and/or transitional domestic violence shelters, some domestic violence survivors are able to secure permanent low-income housing from federal programs, such as tenant-based, project-based, and public housing. Tenant-based housing, known as Section 8, provides vouchers to be used in the private housing market (Park, 2006). Project-based housing provides funds to landlords, who rent apartments at affordable rates to low-income families (U.S. Office of Management and Budget, 2002). Public housing is a federally funded program that provides housing for low-income families at affordable rates (U.S. Department of Housing and Urban Development, 2006). Despite the presence of these programs, they are flawed. Domestic violence survivors are in particular need of immediate housing; however, 44% of all voucher recipients face waitlists of at least one year (U.S. Department of Housing and Urban Development, 2001). Furthermore, domestic violence survivors residing in public housing are not guaranteed confidentiality and are immediately forced out when/if they have an

altercation with the abuser (Baker, Cook, & Norris, 2003; Menard, 2001; Park, 2006).

### Current Response in New York City

New York City's limited response to the housing needs of domestic violence survivors is representative of a national crisis. In the last year, the number of homeless families in New York City has increased from 8,529 to 8,746 (an 11% increase) and more than 50% of homeless mothers in New York City are domestic violence survivors (Coalition for the Homeless, 2006; Markee, 2006). Despite the availability of low-income housing programs, domestic violence survivors continue to fall through the cracks of the New York City housing system. This section will demonstrate the process through which a domestic violence survivor obtains housing in New York City.

#### *Obtaining Housing as a Domestic Violence Survivor in New York City*

New York City receives approximately 7,915 unduplicated annual requests for shelter as a result of domestic violence. There are 39 emergency domestic violence shelters that can accommodate 700 families annually and dozens of publicly and privately funded homeless shelters. Of those who gain acceptance into emergency shelters, 21% enter into one of the seven Tier II/transitional domestic violence shelters in the city. Approximately 60% of those who have gained acceptance into Tier II shelters are able to secure additional permanent housing in the forms of Housing Stability Plus, NYCHA and Section 8 (De O'Conner, 2006).

In 2004, Mayor Bloomberg established the Housing Stability Plus (HSP) Program with the intention of providing low-income housing for people receiving public assistance (NYC Department of Homeless Services, 2004). While many domestic violence survivors are taking advantage of HSP, the monthly subsidy for this housing is decreased by 20% each year and is eliminated after 5 years which requires survivors to make inflated payments without exceeding eligibility requirements for public assistance. Further, undocumented domestic violence survivors and those who could be considered "working poor" are excluded from HSP because they are not eligible for public assistance (Voices of Women, 2005). Despite the drawbacks of this program, 14% of women leaving emergency shelter and 40% leaving Tier II shelters claim HSP housing. Lastly, about 2% of women leaving emergency shelters and 16% of women leaving Tier II shelters enter public housing communities, such as New

### *Conclusion*

The inadequacies of the domestic violence shelter system and lack of permanent housing in New York City have undoubtedly contributed to unprecedented rates of family homelessness. The example of New York City illustrates the low percentages of domestic violence survivors who are able to complete the transition from emergency shelter to Tier II shelter to permanent housing. Sixty percent of domestic violence survivors leave emergency and Tier II domestic violence shelters without the security of safe housing (Coalition of Domestic Violence Shelter Providers, 2006). As a result, they return to the state of vulnerability present at the point at which they first became homeless.

### *Recommendations for Future Policies, Programs, and Research*

#### *Best Practice Suggestions for Policy Makers*

While capable of providing temporary relief for domestic violence survivors, most emergency domestic violence shelters and Tier II/transitional shelters do not enable their clients to obtain low-income permanent housing. Additional funding needs to be allocated to domestic violence organizations in order for them to establish housing programs and hire housing specialists. Funding also has to be allocated to the creation of more emergency and transitional shelters so as to prevent women from being denied admission due to overcrowding. Such funding will allow shelters to be less discriminating in who they are willing to accept.

The housing situations of domestic violence survivors would be improved tremendously if housing vouchers, such as Section 8, were readily available. Vouchers are beneficial because the government subsidizes the rent for the survivor allowing him or her to save in order to acquire permanent housing in the private market. The average wait of 2 years for Section 8 vouchers necessitates that domestic violence survivors be given priority due to their urgent needs (Baker, Cook, & Norris, 2003). Funding for low-income permanent housing programs should also be increased and protocols, such as the “one strike policy,” should be revised to address the unique needs of domestic violence survivors.

#### *Best Practice Suggestions for Shelter Administrators*

Shelter staff are often forced to decide between homeless individuals and

domestic violence survivors when, in reality, these issues often overlap. Program administrators should be educated about the commonality of these two demographics. Those who run emergency homeless shelters need to collaborate with domestic violence agencies to better serve the needs of residents who may be fleeing from violent relationships or homes. These shelters also need to re-evaluate their criteria for homelessness to include domestic violence survivors who “choose” homelessness over the peril of remaining in an abusive home environment.

The administration in domestic violence shelters should communicate with those who manage emergency shelters in order to encourage them to absorb residents who may be in need of domestic violence-specific services, such as therapy and strict confidentiality. Domestic violence shelters should also provide greater assistance to clients in obtaining permanent housing, as opposed to focusing specifically on therapeutic programming. One way shelters can address this need is by creating programs that focus specifically on the housing needs of their residents. This can be done by hiring staff members who specialize in navigating the systems of low-income housing in their communities.

Domestic violence survivors often complain that domestic violence shelter staff members are not empathetic to their circumstances, duplicating the system of power and control they sought to escape. This feeling is fostered by the creation and implementation of arbitrary rules which are enforced in a punitive manner. Shelter Staff needs to receive continued high-quality domestic violence training, consistent supervision and, whenever possible, should consult with domestic violence survivors who have experienced living in the shelter system. Shelter administrators should reassess shelter protocol routinely to ensure that the rules which shelter staff enforce are not exacerbating victimization.

### *Future Research*

Future research on domestic violence and housing should focus on all types of housing-related problems, such as late rent payment, skipping meals, and threats of eviction. Also, researchers should conduct a longitudinal study to look into the long-term effects of housing problems and domestic violence (Baker, Cooke, & Norris, 2003). Bufkin and Bray (1998) make a specific recommendation for researchers to examine the relationship between domestic violence, homelessness, and the criminal justice system. They see the criminal justice system as an effective means of preventing homelessness. Research should identify best practices to guide law enforcement officials in responding to domestic violence incidents. One factor not addressed in

the literature was the effect of economic or financial abuse and its contribution to homeless domestic violence survivors. Another factor under-researched was the frequency of women returning to their abusers and the forces that contribute to this phenomenon.

## Conclusion

As long as the relationship between domestic violence and homelessness continues to be ignored, domestic violence survivors are going to be faced with the choice of homelessness or continued abuse at the hands of their partners. Women and children who are fleeing violent households are at risk of becoming homeless before entrance into the shelter system, after their entrance into the shelter system, and once they have secured low-income housing. The formal systems on which they rely are failing to provide the support that will empower them to become self-sufficient. The healing process cannot be initiated while survivors are enduring the trauma of potential and actual homelessness; an improved quality of life is contingent upon the acquisition of stable and permanent housing. Housing options that are currently available must be enhanced through drastic policy amendments and programmatic changes in addition to further evaluation and research. The choice to leave an abusive relationship is difficult on many levels; rather than neglecting the housing needs of domestic violence survivors, communities need to respond by providing a formal support system which will guarantee that freedom from abuse does not come at the cost of homelessness.

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Taimur Khan | Devika Iyer

*The human immunodeficiency virus, which causes the acquired immunodeficiency syndrome (HIV and AIDS), is a pandemic that militates against public health policy and practice on a global scale. The sex industry is frequently cited as one of the growth factors contributing to increased HIV and AIDS transmission, as well as the spread of sexually transmitted infections across international lines. Therefore, the prevention of HIV and AIDS among commercial sex workers is a major goal of the public health operations of both U.S. and foreign-based organizations working in the sex sector. As it stands, current U.S. laws and policies that dictate the funding of organizations working with sex workers are deleterious to public health and run counter to best practices that prevent the global spread of HIV and AIDS, as well as human rights norms. This article is centrally concerned with the public health implications of the Anti-Prostitution Pledge, which requires foreign NGOs and U.S.-based NGOs working abroad to explicitly oppose the practice of prostitution in order to receive U.S. federal funding for HIV and AIDS prevention among commercial sex workers. Policy prescriptions concerning the public health dimensions of commercial sex work will be offered based on the analysis.*

Operating from the premise that prostitution is conjoined with trafficking in persons for commercial sex, the U.S. government is prohibiting the award of federal funds to foreign non-governmental organizations (NGOs) that appear to promote or support prostitution (The State Department's Office to Monitor and Combat Trafficking in Persons, 2004). U.S. legislation and policies like the President's Emergency Plan for AIDS Relief (PEPFAR), Leadership against HIV and AIDS, Tuberculosis, and Malaria Act (AIDS Leadership Act), and Trafficking Victims Protection Reauthorization Act (TVPRA) require that foreign NGOs and U.S.-based NGOs working abroad make an Anti-Prostitution Pledge, which explicitly opposes prostitution, in order to receive U.S. federal funding for HIV and AIDS prevention targeted at sex industry workers.

The Anti-Prostitution Pledge has negative public health consequences for sex workers at risk of HIV and AIDS transmission as it

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prohibits recipients of U.S. federal funds from using best practices, such as harm reduction and empowerment strategies to prevent HIV among high risk populations. Sex workers are defined as “female, male and transgendered adults and young people who receive money or goods in exchange for sexual services, either regularly or occasionally, and who many or may not consciously define those activities as income-generating” (UNAIDS, 2002). This article will consider aspects of the Anti-Prostitution Pledge, including arguments advanced in support of and in opposition to this policy. Recommendations will be offered on the policy level based on the analysis of the global public health implications of the Anti-Prostitution Pledge.

## Best Practices in Public Health and Human Rights to Counter HIV and AIDS

### *Harm Reduction Model*

Best practices in public health and human rights norms suggest that harm reduction is effective in stymieing the spread of HIV and AIDS among commercial sex workers (Rekart, 2005). Harm reduction as an approach to HIV and AIDS prevention is considered to be a simple, safe, and inexpensive line of response to HIV and AIDS infection that helps avert risk, mitigate harm, and save lives. According to Rekart (2005), HIV and AIDS infection risks associated with commercial sex are reduced using an empowerment-oriented harm reduction model in public health practice with sex industry workers. Harm reduction practices include: occupational health and safety guidelines for brothels, distribution of male and female condoms, training in condom-negotiating skills, and safety tips for street-based sex workers regarding HIV and AIDS preventative strategies.

### *Empowerment: A Harm Reduction Tool*

Empowerment and harm reduction share a synergistic relationship. One of the hallmarks of harm reduction is respect for the individual’s right to self-determination, which is also a core concept of empowerment (Newman, 2003). The harms associated with sex work can be minimized through the empowerment of sex workers. The goal of empowerment is to provide real opportunities for sex workers through services, such as job training, language skills, access to health services, and protection from violence.

### *Human Rights Framework*

The view that positive public health outcomes can be produced by

linking global health policy with respect for human rights is gaining increased acceptance (Loff, et al., 2000). The relationship between human rights abuses and HIV and AIDS transmission among sex workers is bidirectional. Discrimination and human rights abuses are the cause as well as result of HIV and AIDS (Csete, 2004). Many public health interventions, such as the AIDS Leadership Act, consider sex workers hazards to society (Woffers & Beelen, 2003). Restrictive policies around sex work, such as the Anti-Prostitution Pledge, increases stigma driving sex work further underground and increases the likelihood that sex workers will avoid state institutions, including those that deliver health care (Wolffers & Beelen).

#### Anti-Prostitution Laws and Policies: PEPFAR, AIDS Leadership Act, and TVPRA

##### *PEPFAR*

PEPFAR is an executive directive aimed at stemming the spread of HIV and AIDS throughout the world. President Bush recognized HIV and AIDS as a harbinger of a “severe and urgent crisis abroad” in his 2003 State of the Union Address and proposed PEPFAR as a solution (Alliance for Open Society International, Inc. & Open Society Institute, 2005). PEPFAR mandates U.S. funding restrictions on organizations that do not adopt a pro-abstinence approach to the practice of commercial sex work. The executive directive does not consider the human rights standards and best practices in public health discussed above.

##### *AIDS Leadership Act*

PEPFAR has given impetus to the creation of a cluster of laws and policies, one of which is the AIDS Leadership Act. In May 2003, the U.S. Congress passed the AIDS Leadership Act (22 U.S.C. §§ 7601-7682, 2003), which bars the use of federal funds to “promote, support, or advocate the legalization or practice of prostitution or sex trafficking” (22 U.S.C. § 7631(e), 2003). The law requires organizations receiving U.S. HIV and AIDS funding to agree with the Anti-Prostitution Pledge and adopt a policy explicitly opposing prostitution and sex trafficking. Organizations that do not denounce prostitution could continue to lose billions of dollars in U.S. federal funding, thus impeding their efforts to prevent the spread of HIV among sex workers and undermining efforts to promote the fundamental human rights of all persons (CHANGE, 2005).

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The AIDS Leadership Act is currently applicable to foreign NGOs receiving bilateral U.S. HIV and AIDS funds and U.S.-based NGOs working abroad. Although the restrictions of the law do not currently apply to multilateral organizations, there is considerable concern that the extension of the restrictions is inevitable (CHANGE, 2005). In May 2005, the Centers for Disease Control implemented funding restrictions on the Joint United Nations Programme on HIV and AIDS (UNAIDS) and World Health Organization sub-grantees, which were later abrogated after widespread public denunciation (CHANGE).

### *TVPPRA*

The TVPPRA prohibits U.S. federal funding for organizations that tacitly “promote, support, or advocate the legalization or practice of prostitution” (22 U.S.C. §§ 7101-7110, 2003). The funding restrictions mandated by the TVPPRA bar organizations that work with trafficking victims from employing a range of modalities to improve the public health of this group using a human rights-based framework. Due to the conflation of prostitution with trafficking in persons, organizations working to aid and empower victims of trafficking lose necessary funding to stave off health harms surrounding sex work (Ditmore, 2003).

### Proponents of the Anti-Prostitution Pledge

In a December 2002 National Security Presidential Directive, the U.S. Government adopted an abstinence-based and abolitionist position against legalized prostitution. This position was adopted based upon the premise that prostitution is a harmful and dehumanizing practice that stimulates human trafficking, and the vast majority of sex workers want to escape from this practice (The State Department’s Office to Monitor and Combat Trafficking in Persons, 2004). From the vantage point of the U.S. Government, legalization of prostitution increases the demand for commercial sex work, thus providing market opportunities for criminals who traffic people into prostitution. Furthermore, the U.S. Government contends that legalized prostitution makes it difficult for law enforcement officials to identify and penalize criminals who engage in trafficking (The State Department’s Office to Monitor and Combat Trafficking in Persons). Based on this conflation between prostitution and trafficking, the U.S. Government decided to implement restrictions on HIV and AIDS funding to organizations that work with sex workers.

Anti-Prostitution Pledge advocates, also known as abolitionists, further argue that abstinence from sex and abolition of prostitution should

underpin the HIV and AIDS prevention efforts of organizations working in the sex sector. Abolitionists view sexual commerce as degrading and dehumanizing, characterizing sex work and trafficking in persons as a form of modern day slavery (The State Department's Office to Monitor and Combat Trafficking in Persons, 2004). Many ideologues from the Christian Right, as well as several radical feminists endorse this view of commercial sex work. Radical feminists who support the Anti-Prostitution Pledge view prostitution as a coerced form of male-dominated wage slavery, as well as a feminized type of exploitation reflecting patriarchy, which is harmful to all women (Jaggar, 1997). Similarly, members of the Christian Right supporting the Anti-Prostitution Pledge oppose sex work on moral grounds because these members define legitimate sexual contact as relations between two married people of the opposite sex for purposes of procreation only (CHANGE, 2004).

Anti-Prostitution Pledge advocates assume that all sex workers are perforce victimized, do not choose to engage in sex work, and seek to escape this practice. In addition, they argue that trafficking in persons is bound up and inextricably linked with the sex trade. Furthermore, abolitionists reason that the harm reduction model of prostitution encourages the practice of sex work and increases the market demand for the profession, causing a rise in persons trafficked into commercial sex on the supply side (The State Department's Office to Monitor and Combat Trafficking in Persons, 2004).

### Opponents of the Anti-Prostitution Pledge

Public health practitioners working with sex workers suggest that the U.S. government's pro-abstinence, anti-prostitution stance towards HIV-prevention aid is a paternalistic and unrealistic approach (Ditmore, 2005). Therefore, pro-Anti Prostitution Pledge arguments require a more complicated and human rights based understanding of sexual commerce.

#### *Harm Reduction Approach*

Opponents of the Anti-Prostitution Pledge argue that harm reduction is a best practice and funding should not be eliminated for organizations implementing this approach (CHANGE, 2004). As discussed earlier, empirical evidence of public health operations involving sex workers suggests the greater efficacy of the harm reduction model in countering the spread of HIV and AIDS among sex workers (Newman, 2003). For example, by bringing a harm reduction model to bear on public health interventions in India, the Sonagachi Project, an

HIV-prevention program in Calcutta, significantly lowered HIV seroprevalence rates among sex workers in the city (Newman). The Sonagachi Project couples harm reduction principles with empowerment strategies to minimize the health risks of sexually transmitted diseases among sex workers. Human Rights Watch estimates that the Sonagachi Project's harm reduction approach has impacted more than 30,000 sex workers at risk for HIV and AIDS (Human Rights Watch, 2005). UNAIDS has also credited the Sonagachi Project as a best practice model for the proven effects in public health.

Furthermore, harm reduction is the precipitating factor behind the successful public health outcomes achieved among sex workers in many countries. For example, in Brazil, harm reduction and HIV and AIDS prevention programs have been lauded by the United Nations as among the best in the developing world (Reel, 2006). Current estimates indicate that there are less than 600,000 HIV-infected people in Brazil, which is half the number forecasted by the World Bank a decade ago. Through state-funded sex education and prevention workshops, the distribution of free condoms, and informational pamphlet dissemination, Brazil has managed to effectively reduce the HIV and AIDS rate in the country (Reel).

### *International Human Rights Violations*

Opponents to the Anti-Prostitution Pledge contend that this policy is in violation of the fundamental human rights of sex workers and in conflict with a corpus of international human rights instruments and laws, such as the Universal Declaration of Human Rights (UDHR) (CHANGE, 2005). The rights emanating from the UDHR, including the right to "security of person," freedom from "inhuman or degrading treatment," and "equal protection of the law," are eroded by the Anti-Prostitution Pledge (Butcher, 2003). Whereas international human rights laws lack enforcement power, as their implementation rests on governing bodies, laws and policies issuing from the U.S. federal government compel observance due to the threat of loss in funding.

It is evident that multinational institutions, including the United Nations and foreign national leaders in HIV- and AIDS-affected countries exert little pressure on U.S. federally-funded HIV and AIDS programs (Csete, 2004). Through its proscription of harm reduction as an approach to the public health of sex workers, the Anti-Prostitution Pledge counteracts human rights.

Furthermore, access to healthcare is a fundamental human right as stated in Article 25 of the UDHR (UDHR, 1948) and the constraints wrought by the Anti-Prostitution Pledge deprive sex workers of their basic right to health. The



limited range of public health interventions sanctioned by the AIDS Leadership Act fly in the face of best practices and human rights standards forcing recipient organizations of U.S. funding to adopt less effective HIV and AIDS preventive strategies.

### *U.S. Constitutional Concerns and Challenges*

Opponents of the Anti-Prostitution Pledge raise constitutional concerns about this policy, arguing that it violates the right to freedom of speech enshrined in the First Amendment (Human Rights Watch, 2005). By forcing organizations to explicitly oppose prostitution, the Anti-Prostitution Pledge compels speech, thereby violating the First Amendment to the Constitution by requiring domestic and foreign-based organizations working in public health to align with the U.S. government's policy position. Anti-Prostitution Pledge advocates also believe that funding restrictions under the AIDS Leadership Act violate the First Amendment because the vagueness of the Pledge requirement allows the law to be applied arbitrarily (Open Society Institute, 2005). Finally, organizations working with sex workers contend that the Anti-Prostitution Pledge unconstitutionally undermines public health interventions by forcing them to either adopt an anti-prostitution policy or forego federal funding, which may limit the effectiveness of their HIV and AIDS prevention efforts (Alliance for Open Society International, Inc. et al., 2005).

### *Public Health Implications of the Anti-Prostitution Pledge*

Opponents of the Anti-Prostitution Pledge argue that current legislation is antithetical to best practices that promote empowerment (CHANGE, 2005). Empowerment strategies intended to provide commercial sex workers with economic alternatives to sexual commerce are being affected by the government policy. For example, NGOs in Cambodia have stopped providing avenues out of sex work, such as English-language classes, for fear they would be seen as promoting prostitution (CHANGE). Additionally, the intervention strategies of EMPOWER Thailand, an organization that helps sex workers obtain high school diplomas and employment skills, were jeopardized as a result of the Anti-Prostitution Pledge (CHANGE, 2003). In short, the Anti-Prostitution Pledge can be said to have a perverse effect on the public health operations of organizations working with sex workers.

Furthermore, opponents of the Anti-Prostitution Pledge suggest that the pro-abstinence agenda is myopic insofar as it alienates sex workers, the very population essential to prevent further spread of HIV and AIDS, by

stigmatizing commercial sex work and calling for its abolition (CHANGE, 2005). Implicit in the Anti-Prostitution Pledge is the denial of the lived and embodied experiences of commercial sex workers. The condemnation of sexual commerce that organizations working with sex workers are compelled to adopt under U.S. laws and policies ratchet up the stigma around this line of work (CHANGE).

### Policy Recommendations

In consideration of the sex work harms and public health concerns that this government policy engenders, we offer the following policy recommendations to the federal government of the United States:

*Amendment of the AIDS Leadership Act with a View towards Greater Conformity with Constitutional Guarantees, Human Rights Norms, and Best Practices in Public Health*

When sex workers are denied access to condoms or any other prevention technology or strategy, it violates both human rights principles and medical ethics (CHANGE, 2004). Furthermore, a reliance on abstinence will leave millions of people without the knowledge, information, and skills necessary to prevent infections (CHANGE). Hence, U.S. government commitment is required to maintain funding for condom procurement and delivery to decrease behavioral risk of HIV and AIDS infection among sex workers globally.

*Revoke the Anti-Prostitution Pledge and Have a Re-authorization Act Excluding the Opposition to Sex Work*

There is concern in policy and public health circles that the Pledge requirement undermines HIV and AIDS prevention programs specific to sex industry workers and that organizations working with sex workers will abandon innovative and effective programs for fear of losing funding. As a result, the Pledge requirement could further stigmatize commercial sex workers, leading to disastrous consequences for global public health. Hence, a revocation of the Anti-Prostitution Pledge is needed.

*Include Commercial Sex Workers Affected by Laws and Policies Germane to Prostitution in Policy Decisions Concerning the Sex Trade*

Sex industry workers affected by laws and policies concerning prostitution should be included in policy decisions about transactional sex

because they are associated with the transmission and prevention of HIV and AIDS. The Pledge requirement alienates sex workers who are already socially marginalized because of widespread stigma and discrimination. Evidence suggests that public health interventions repudiating targeted populations produce ineffective outcomes. Including sex workers in policy making about people-in-prostitution reduces social stigma.

*Broad-based Consultation with Experts across the Professional Spectrum*

Consult with a broad range of experts including but not limited to social work practitioners, public health professionals, and organizations working in the sex sector, to effectively create an overarching policy that productively stems the spread of HIV and AIDS. Broad-based consultancy ensures transparency in policymaking, consistency with U.S. and international human rights law, and the promotion of best practices in public health (CHANGE, 2005).

*Avoid Conflating Sex Work with Trafficking*

The U.S. government must avoid conflating sex work with trafficking as it ignores other categories of trafficking, including trafficking for forced labor. The conflation between human trafficking and trafficking for sex eclipses other forms of internal and cross-border trafficking, which promotes a narrow view of this transnational activity. Linking trafficking uniquely to sex work is harmful on the policy level as it may encourage situations of abuse for persons trafficked into other industries to go unnoticed and unaddressed (Ditmore, 2002).

*Provision of U.S. Funding to Organizations Working with Sex Workers That Do Not Espouse a Specific Policy on Prostitution*

Retract current funding restrictions in legislation and espouse a harm reduction model and human rights based approach to sex work. Specifically, amend the TVPRA with a greater conformity towards human rights standards and best practices in public health.

Conclusion

Productive public health outcomes can be achieved more successfully through human rights and empowerment mechanisms coupled with harm reduction models rather than an anti-prostitution and abstinence-only approach to commercial sex work. HIV and AIDS is a public health concern of global proportions. As it stands, the AIDS Leadership Act will accelerate the

transmission of HIV and AIDS, increasing morbidity and mortality rates among sex workers as well as the larger population. Therefore, a rethinking of U.S. government policy with regard to HIV and AIDS prevention is in order.

At this writing, several U.S.-based NGOs including Alliance for Open Society International, Pathfinder International, Open Society Institute, and DKT International have filed suit in New York and Washington D.C. District Courts arguing that the Anti-Prostitution Pledge violates their constitutionally-protected right to free speech (Bristol, 2006). District court judges in New York and Washington D.C. decreed that enforcement of the Anti-Prostitution Pledge would cause the plaintiff organizations to suffer irreparable harm, thus violating the First Amendment of the U.S. Constitution (05-cv-8209 (S.D.N.Y.)). While this ruling provides plaintiff U.S.-based NGOs with a legal remedy, it does not provide legal relief to foreign NGOs who do not have U.S. constitutional rights and are potentially gagged by the Pledge requirement (Bristol, 2006).

On February 27, 2007, a federal appellate court for the District of Columbia upheld the constitutionality of the Pledge requirement overturning the lower court's decision (Brennan Center for Justice, 2007). Circuit judges of a U.S. Court of Appeals decided that the funding conditionality under the AIDS Leadership Act does not compel appellate organization, DKT International, to advocate the government's position on prostitution and sex trafficking, but rather communicates the message the government chooses to fund (06-cv-5225 (D.C. Cir. 2007)). At this writing, it is uncertain as to whether or not DKT International will appeal the ruling concerning the Pledge requirement at issue. The judicial outcome of a separate action brought by the U.S. government appealing the decision of the New York district court also remains to be seen.

With more than 40 million HIV- and AIDS-infected people worldwide and the loss of funding from the U.S., one of the largest donors of HIV and AIDS prevention funding globally, implications for the public health of sex workers are disastrous (Bristol, 2006; Open Society Institute, 2004). Human suffering caused by the scourge of HIV and AIDS can be more effectively prevented on the local, national, and international level if the Pledge requirement is jettisoned for evidence-based, best practices in public health.

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Jennifer Zaleski

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*Although many articles and books discuss the ethics of end-of-life issues, few publications are written specifically for social workers and social work students. The lack of relevant literature is problematic because social workers have different ethical obligations than other health care professions who work with clients who are contemplating assisted suicide. This paper will analyze the ethical dilemma that social workers face in end-of-life issues by reviewing the material available to social workers such as the NASW Code of Ethics and the relevant NASW Policy Statement. This paper finds that the different sources of information provided by NASW do not fully address the complexities surrounding the social work profession and end-of-life issues. Additional training and continuing education courses should be offered and a stronger policy statement is needed that explores the complexities faced by social workers in end-of-life care.*

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Advances in medical capabilities and technology have recently made it possible to extend life through artificial means (NASW, 2002). The National Association of Social Workers (NASW) acknowledges that, “unwanted utilization of medical technology may lead to a lessened quality of life, loss of dignity, and a loss of integrity for patients” (NASW, 2002, p.60). Social workers are being called upon to deal with quality of life issues as well as choices related to assisted suicide. Because of its recent and sudden growth mixed with the unavailability of clear guidelines, end-of-life care is an area of practice that many social workers are unprepared and unable to deal with effectively (Csikai & Raymer, 2003). To determine the appropriate course of action for end-of-life care, social workers must examine the pertinent resources, including NASW policy statements, available state guidelines, and the NASW Code of Ethics. Reviewing the available material for social workers reveals that current policy and resources for social workers are inadequate and the issue needs to be addressed further.



## NASW Policy Statement

The NASW frequently publishes policy statements to help guide social workers in ethical dilemmas not specifically covered in the Code of Ethics. The NASW policy statement, "Client Self-Determination in End-of-Life Decisions," states that client self-determination is "the right of the client to determine the appropriate level, if any, of a medical intervention and the right of clients to change their wishes about their treatment as their condition changes over time or during the course of their illness" (2003, p. 59). The appropriate role of social workers in end-of-life care is to help patients express their thoughts and feelings, to facilitate exploration of alternatives, and to deal with grief and loss. This policy statement justifies social workers' facilitation of a client's end-of-life decision making process, although it allows a caveat for those social workers who wish not to participate when it states that "social workers are permitted to participate in assisted suicide depending on their personal beliefs, attitudes, and value systems" (NASW, 2003, p. 61).

## The Oregon Death with Dignity Act

Because Oregon is the only state where physician-assisted suicide has been legalized, the Death with Dignity Act is a model through which the role of social workers in the end-of-life debate can be explored. Whereas a doctor is committed to the beneficence of the patient, social workers in Oregon are committed to fostering the client's self-determination by providing information about assisted suicide, answering questions, and forming a trusting relationship, thus empowering the client to make autonomous decisions about how to live out his or her final days (Ganzini, et al., 2004). The values and mission of social work distinguish social workers from other professions; therefore, social workers must handle assisted suicide differently than members of other professions.

The Death with Dignity Act legalizes physician-assisted suicide (Ganzini, et al., 2004) for terminally ill Oregon residents who are 18 years or older with a life expectancy of six months or less, as diagnosed by a primary physician and a consulting physician. The Death with Dignity Act enacts procedural safeguards to determine eligibility for a lethal prescription. In order to be considered for this lethal dose, a patient must have a terminal illness with only six months to live, make a written request for a prescription, and two oral requests, which must be separated by at least 15 days (Werth & Wineberg, 2005).

The prescribing physician must inform the patient about alternatives to lethal medication, as well as request that family members be notified of the patient's decision. It is also the responsibility of the prescribing physician to assess whether the patient's decision is informed and voluntary, and two additional people are to serve as witnesses. Physicians are required to establish patient competency and complete a patient assessment prior to prescribing a lethal prescription.

Eligibility for a lethal prescription under the Death with Dignity Act also requires that the patient's competency be established. Competency is usually assumed unless a court has declared the person incompetent or a mental illness raises doubts about competence (Farrenkopf & Bryan, 1999). A patient can establish mental capacity by showing he or she can make clear choices, is able to understand and accurately apply medical information to his or her condition, and can demonstrate internally consistent reasoning (Farrenkopf & Bryan). If a physician finds the patient's judgment impaired, they must refer the patient to a psychologist or a psychiatrist for a more thorough assessment (Werth & Wineberg, 2005). During this assessment, the patient should demonstrate his or her understanding of information relevant to his or her decision, such as the consequences of the decision and the risks and benefits of alternatives.

### NASW Code of Ethics

#### *Service*

*"Social workers elevate service to others above self-interest. Social workers draw on their knowledge, values, and skills to help people in need and to address social problems"* (NASW, 2000, Ethical Principles, para 2). Social workers are obligated to respect a client's right to self-determination, even when the client's goals conflict with the worker's individual moral framework. Those opposed to the Act may argue that the principle of service is limited to those acts which pose no harm to the client or others. John Stuart Mill (1975) justifies interfering with autonomy only if it prevents infliction of harm upon others, not oneself, when he stated, "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others ... Over himself, over his own body and mind, the individual is sovereign" (p. 11). Supporters for the Death with Dignity Act also assert that a client's sense of "human worth" increases if he or she is able to gain control over the dying process (Farrenkopf & Bryan, 1999).

### *Social Justice*

*“Social workers are sensitive to cultural and ethnic diversity and strive to end discrimination, oppression, poverty, and other forms of social injustice”* (NASW, 2000, Preamble, para 2). It is the responsibility of social workers to help meet the needs of all populations, especially those who are vulnerable and oppressed. Critics of the Death with Dignity Act have expressed a fear that people who choose physician assisted suicide would be uneducated, poor, uninsured, or receiving inadequate end-of-life care (Csikai & Manetta, 2003). Some critics have suggested that people would turn to assisted suicide so as to not burden their families. However, palliative care is covered through the Oregon Health Plan. As a result, people do not have to worry about bankrupting their loved ones (Werth & Wineberg, 2005). In addition, 98% of those who have utilized physician assisted suicide have had private insurance or were covered by Medicare or Medicaid. While these reports suggest that the Death with Dignity Act does not target the poor, the issue needs to be examined in more depth.

### *Dignity and Worth of a Person*

At the forefront of arguments surrounding social workers and the Death with Dignity Act is the dignity and worth of a person. It is the responsibility of social workers to *“promote clients’ socially responsible self-determination”* (NASW, 2000, Ethical Principles, para 4). Physician collected data has highlighted the importance of self-determination on end-of-life decisions. Patients have expressed that their reasons for choosing physician assisted suicide include future loss of control, being a burden, being dependent on others for personal care, loss of dignity, being restricted to bed more than 50% of the time, and experiencing severe depression (Csikai & Manetta, 2002). The values of the social work profession refer to strongly-held beliefs about the individual’s right to free choice and opportunity (Hepworth et al., 2003). Supporters maintain that the law is beneficial even to those terminally ill people who do not utilize a lethal prescription, because they gain peace of mind from knowing that the end-of-life is under their control (Greenhouse, 2005), illustrating the importance of autonomy on client satisfaction.

*“Social workers may limit clients’ right to self-determination when, in the social workers’ professional judgment, clients’ actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others”* (NASW, 2000, Social Workers’ Ethical Responsibilities to Clients, para 2). This statement asks social workers to limit clients’ self-determination in some cases,

but there is no clear distinction as to what actions will pose imminent risks for clients. Social workers have previously been advised that upholding the client's right to self-determination is a pillar of social work, but are now being instructed that upholding the beneficence of the client may now take precedent.

### *Competence*

*“Social workers should provide services and represent themselves as competent only within the boundaries of their education, training, license, certification, consultation received, supervised experience, or other relevant professional experience”* (NASW, 2000, 1.04 Competence, para a). NASW does not define at what point social workers have an obligation to participate in end-of-life care, or at what point one is considered competent in a given area. “When generally recognized standards do not exist with respect to an emerging area of practice, social workers should exercise careful judgment and take responsible steps to ensure the competence of their work and to protect clients from harm” (NASW, 2000, 1.04 Competence, para c). Reamer (1998) suggested that social workers take into account a number of resources when encountering an ethical challenge: ethical theory, literature on ethical decision making strategies, social work practice theory and research, relevant laws and regulations, agency policies, and other relevant codes of ethics. The NASW also calls for state chapters to encourage their members to participate in local, state, and national level committees and task forces to study the issues of end-of-life care, in order to better inform themselves (Csikai & Manetta, 2002). In the absence of generally recognized standards, social workers should refer to the guidelines and principles listed in the Code of Ethics.

## Recommendations

### *Practice Recommendations*

Working with clients who are making end-of-life decisions is an area of discomfort to many people, including social workers. Social workers should be aware of any conflicts between personal and professional values and deal with them responsibly (NASW, 1996). Social workers should be informed of current federal and state legislation, and have an understanding of how this legislation intersects with their own values and beliefs.

Neither the Code of Ethics nor the policy statement addresses the relative importance of values surrounding the end-of-life debate. In one study, many social workers expressed views that were inconsistent with the policy

statement that defines end-of-life decisions as, “the choices made by a person with a terminal condition” (Manetta & Wells, 2001). Over half of the participants in this study favored physician assisted suicide even in situations where there was no fatal illness present, which is inconsistent with the Death with Dignity Act. This study illustrates how social workers’ personal beliefs and values can be inconsistent with NASW standards or state guidelines, and it demonstrates the importance of addressing this issue in greater detail.

### *Policy Recommendations*

Although Oregon is the only state with physician-assisted suicide, it is important for social workers in all other states to advocate for the increased quality of care of patients at the end of their lives. Social workers should specifically advocate for public policy that respects clients’ rights to self-determination. Some of the most critical barriers to optimal end-of-life care are limited availability and coverage, ineffective service delivery, and poor provider communication (Yabroff & Mandelblatt, 2004). A large part of overcoming these and other barriers should be achieved through continuing education and training.

Social workers need more guidelines and guidance to determine the proper course of action when working with clients who are contemplating assisted suicide. A stronger policy statement is needed that explores the complexities faced by social workers in end-of-life care, rather than simply exploring the issue of assisted suicide. This policy statement should outline in greater detail the role and responsibilities of social workers, formally address the conflict between social workers’ professional and personal values, and mandate that social workers receive more education and training in order to improve their competency in end-of-life issues.

### *Conclusion*

Social workers have a different role in end-of-life care because of their unique purpose and perspective. In order to make ethical decisions, social workers must examine state guidelines, NASW policy statements, and the Code of Ethics, as well as their own values and beliefs. The resources available to social workers for ethical dilemmas, such as the Code of Ethics and NASW policy statements, can further complicate decision-making rather than help to distinguish the ‘right’ answers. A stronger and clearer policy statement is necessary to address the complexities surrounding end-of-life issues.

Training should be offered to social workers entering the field of aging, and more continuing education courses should be mandated for social workers who are continuing in the field. Social workers can no longer afford to have only a vague understanding of prevailing ethical standards (Jayaratne et al., 1997).

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## SOCIAL WORK PRACTICE WITH CHILDREN PERINATALLY-INFECTED WITH HIV: CONSIDERATIONS REGARDING DIAGNOSTIC DISCLOSURE

Natasha K. Nalls

*The development of antiretroviral therapies (ARTs) has significantly lengthened the lifespan and changed the life course of most individuals infected with HIV and AIDS in the United States. Furthermore, ART use during pregnancy has significantly reduced the rate of mother-to-child (perinatal) HIV transmission. While perinatal infection rates among children in the United States have declined since the 1990s, ART regimens became standard treatment protocol, there remains a population of children entering adolescence who were born HIV-positive. This paper discusses: 1) the importance of diagnostic disclosure of HIV and AIDS status to infected children, 2) stigma and the disclosure process with children, and 3) the role of clinical social workers in facilitating the disclosure process.*

The most common means of human immunodeficiency virus (HIV) transmission to children in the United States is through mother-to-child vertical transmission during pregnancy (Center for Disease Control [CDC], 2006a). Perinatal transmission increased throughout the 1980s and peaked during the early-to mid-1990s, during which time an estimated 1,750 children were born perinatally-infected each year (CDC, 2004; Lindegren, et al., 1999). Since the beginning of the HIV and AIDS epidemic in the United States, about 57% of perinatally-infected children have died as a result of AIDS-related complications (CDC, 2004; 2006a). Since the mid-1990s, the introduction of ARTs combined with HIV and AIDS testing among pregnant women has significantly reduced the risk of mother-to-child HIV transmission (CDC, 2006a; Lindegren, et al., 1999). By the year 2000, the number of perinatal HIV and AIDS infections had decreased to about 325 annually. Currently, an estimated 9,419 perinatally-infected children are living in the United States (Wiener & Battles, 2006). Still, disclosure of an HIV and AIDS diagnosis remains a challenging topic for parental caregivers. Research indicates that 25 to 75% of school-aged children with HIV or AIDS do not know their status (Blasini, et al., 2004; Lester, et al., 2002; Mellins, et al., 2002). The American Academy of Pediatrics recommends that all HIV-infected and AIDS-positive



school-aged children be disclosed to and educated regarding their diagnosis and health status (Committee on Pediatric AIDS, 1999). The majority of perinatally-infected children living with HIV and AIDS are African American (60%) and Latino (20%) (CDC, 2004; CDC, 2006a).

### Stigma and HIV and AIDS Diagnostic Disclosure

The use of ARTs has made perinatally- and adult-acquired HIV a disease comparable to cancer in terms of its clinical course as a chronic, long-term, sub-acute, yet life-threatening disease (Mellins, et al., 2002; Brown, Laurie, Pao, 2000). However, unlike cancer, HIV and AIDS has greater social stigma, perhaps related to the high HIV transmission rates and short-term life expectancy of AIDS-infected homosexual and substance abusing populations during the 1980s and 1990s (Fife & Wright, 2000). The stigma is highly related to the fact that the virus is often transmitted through sexual contact (Valdiserri, 2002). Though male-to-male sexual contact remains a risk factor, the risk of HIV transmission through heterosexual sex and drug use is greater still. Moreover, research has shown that many misconceptions exist about the actual modes of HIV transmission (Herek, Capitanio, & Widaman, 2002).

Several factors affect a caregiver's decision to tell a child of his or her HIV or AIDS status. Social stigma is a primary reason why parents are reluctant to disclose. A desire to protect the infected child from social ostracism combined with a sense of guilt related to mother-to-child transmission of the virus may plague the family system (Committee on Pediatric AIDS, 1999; Blasini, et al., 2004). In addition, parents may be concerned that the child may then disclose to others, jeopardizing the social standing of all family members (Nehring, 2000; Lashley & Malm, 2000). Fife and Wright (2000) noted that the social stigma associated with HIV and AIDS is related to internalized feelings of shame and social isolation.

The current literature examining HIV and AIDS disclosure to children has posited contradictory research findings about the impact of disclosure on a child's health and mental health outcomes. Some studies have shown that HIV and AIDS status disclosure to children generally results in positive outcomes for both children and their parental caregivers. Parental caregivers have reported a sense of relief after disclosure, as well as lower levels of stress, compared to parental caregivers who have not disclosed (Blasini, 2004; Committee on Pediatric AIDS, 1999). Contrary to caregivers' concerns related to social stigma, there are no indications that knowledge of HIV and AIDS diagnosis

significantly increases psychological distress or mental health problems among children (Wiener & Battles, 2006). A growing body of literature suggests that children who are disclosed to have higher self-esteem and are less depressed compared to their non-disclosed counterparts (Mellins, et al., 2002; Committee on Pediatric AIDS 1999).

Mellins, et al. (2002) suggested that the burden of an “unknown secret” may be psychologically taxing and create worrisome thoughts for a child. Another study suggested that the occurrence of psychiatric disorders among perinatally-infected youth were comparable to the occurrence in non-infected youth, suggesting that perinatally-infected HIV youth were not at greater risk for mental health difficulties (Mellins, 2006). Furthermore, disclosure seems to be an important factor in garnering social support around the diagnosis and the child’s care. The earlier children learn about their HIV status, the more people they disclose to by the time they reach adolescence (Wiener & Battles, 2006). Having friends and relatives who know these children’s medical status is important for social support. Children and adolescents living with HIV and AIDS who are not disclosed to exhibit more confusion about their illness and medication compliance (Abadia-Barrero & LaRusso, 2006). Over time, these children may become cynical about their care and develop attitudes of shame and anger.

Other research, however, has highlighted the negative outcomes of disclosure. For example, disclosing HIV and AIDS status to friends and family may heighten caregiver and child stress levels and feelings of anger, particularly because disclosure to family and friends may be only in response to the child’s declining health (Ledlie, 1999). These increased feelings of stress and anger, in turn, may decrease medication adherence (Garvie, 2006). Furthermore, some parental caregivers have reported that, following disclosure, their child experienced emotional distress due to concerns about his or her own long-term reproductive and family planning (Mellins, 2002). Contrary to other findings regarding perinatally-infected children, Gaughan, et al. (2004) reported a higher incidence of psychiatric hospitalizations among children and adolescents living with HIV and AIDS along with a significantly higher occurrence of depression and behavioral disorders. Still, despite the lack of consensus, Battles and Wiener (2002), in a review of the literature, noted that most researchers found that disclosure is positively related to social support, feelings of self-competence, and decreased behavioral problems among children.

### The Diagnostic Disclosure Process

As children perinatally-infected with HIV and AIDS age, disclosure of their HIV and AIDS status by caregivers, medical professionals, social workers, and psychologists becomes a sensitive yet important clinical issue that must be addressed. Disclosure of HIV and AIDS status at an early age is important for several reasons. First, children perinatally-infected with HIV and AIDS are most likely to be urban, low-income, and African American or Latino (CDC, 2004). Studies have shown that this population is especially at risk for an early onset of sexual activity and drug use (CDC, 2004). As a result, this HIV and AIDS infected sub-population is at an increased risk of transmitting the virus via sexual intercourse and drug use (Browning, Leventhal, & Brooks-Gunn, 2004).

In addition, research has suggested a significant correlation between disclosure and positive health status as measured by viral load. Children who know their health status are more likely to adhere to an ART and have a lower viral load, demonstrating a better health status (Blasini, et al., 2004). This is important because failure to adhere to an ART regimen may result in treatment resistance, therefore compromising the child's long-term health prognosis (Matsui, 1997). In this way, disclosure is closely related to transmission prevention and the child's health maintenance.

Ideally, disclosure should be conducted gradually throughout the child's development and include the support of health and mental healthcare providers. Disclosure should never occur as a "single revelation" (Domek, 2006). Parental, peer, and mental health staff support are all key to successful disclosure (Blasini, et al., 2004). As with grieving around other chronic, potentially terminal illnesses, children and adolescents with HIV and AIDS will likely go through the following stages of grieving: anger, bargaining, depression, and ultimately, acceptance (Blasini, et al., 2004; Kindy-McPherson, 2005). Immediately following disclosure, children report feeling shocked, sad, angry, worried, and confused (Mellins, et al., 2002). Over time, children's anxious feelings generally become more neutralized, and many have reported feeling hopeful about their prognosis. Domek (2006) noted that it may take children some time to understand the nature of their diagnosis, necessitating an ongoing, open dialogue of what the disease is and what the diagnosis means. In addition, disclosure may provide a context to reveal other family secrets, such as other infected family members, the child's biological parents, the child's health prognosis, and that the child was perinatally-infected.

Though families may be in denial and refuse to disclose to their children, it is not uncommon for children to "accidentally" learn of their diagnosis by overhearing conversations or reading something related to their health status

(e.g., medical charts, insurance paperwork, or school medical records). Or, for example, a child may discern that he or she has a medical condition based on family members' behaviors, a consistent medication regimen, and ongoing medical care (CHAMP+, 2007; Lester, et al., 2002). This type of accidental disclosure is dangerous and should be avoided because emotional isolation may develop as children independently attempt to make sense of what their diagnosis means and why it has been hidden from them (Blasini, et al., 2004).

Despite these risks, social work clinicians should not force a parental caregiver to disclose to a child, and they should remain non-judgmental about the guardian's decision around disclosure; clinician respect for each family's right to self-determination is most important. The clinician's first and foremost role is to provide ongoing support to the family system, taking into consideration the family's community and ongoing stressors (Kindy-McPherson, 2005; Lester, et al., 2002). Less expressive and less communicative families, who are also less likely to disclose to their children, may need additional support (Lester, et al.).

The disclosure process should take into consideration the child's age, maturity, cognitive functioning levels, and ability to handle the diagnosis (Committee on Pediatric AIDS, 1999; Lester, et al., 2002). While younger children should receive simple explanations about their medical condition, older children should be provided with full disclosure and be encouraged to actively participate in their own medical care (Committee on Pediatric AIDS, 1999). Due to developmental differences, children and preadolescents understand that HIV and AIDS are serious illnesses, but they do not relate it to their future, as adolescents do (Blasini et al., 2004). This likely reflects adolescents' emotional, social, and physical development, and their general interests in romantic relationships and considerations around family planning.

### Implications for Social Work Practice

Social workers may encounter perinatally-infected youth in a number of contexts, including hospitals, outpatient pediatric AIDS clinics, child welfare agencies, and schools. Within these settings, where there are few interventions tailored to the needs of perinatally-infected children, social workers are in a unique position to provide mental health service support for this population's ongoing and emerging mental health needs. Social workers' skill sets in the areas of engagement, assessment, advocacy, case management, and crisis intervention, combined with their conceptual grounding in ecosystems theory, make them especially qualified to assist families facing enormous psycho-

social-environmental problems related to the disclosure process.

A full understanding and consideration of the child's particular family circumstance and health status is imperative. The child's family represents a group directly affected by HIV and AIDS. At a social worker's point of contact, the child may be living with an infected parent, a non-infected parent, within the foster care system, or with another family member, such as a grandmother or uncle. Furthermore, the child may also have infected siblings and other family members, or be the only infected person within the entire family. In addition, some perinatally-infected children may be very healthy; others, however, may be chronically ill, very symptomatic, and present with significant immunological deterioration (Lester, et al., 2002). The mental health status and daily concerns of these two populations may be very different.

Psychodynamic, emotional peer support groups for HIV-infected adolescents can help reduce the risk of depression and increase medication adherence (Funk-Brentano, 2005). Disclosure to preadolescents and adolescents should include a psycho-educational component and at least some discussion about self-care and responsibility related to future independent living (Battles & Wiener, 2002). Clinical work with this population should include a thorough sexual education component and foster the development of communication skills related to negotiating safe-sex practices and disclosing HIV and AIDS status to sexual partners. Furthermore, "one stop care" that offers counseling and social support, case management services, standard medical care, reproductive care and education, enables social service and medical providers to collaborate and offer responsive, comprehensive care along a continuum that addresses this population's unique needs (Levine, Aaron, & Foster, 2005).

### Conclusion

The onset of adolescence combined with the uncertainty of a chronic, life-threatening, and highly stigmatized illness undoubtedly creates a context for fear, anxiety, and feelings of isolation among perinatally-infected HIV and AIDS positive children and adolescents. Disclosure, especially early on, may buffer these feelings, providing the child with an increased sense of hope, confidence, and self-esteem. These children are likely to confront a host of other issues, including poverty, discrimination, mental health issues, violence, sexual abuse, limited access to health care, and lack of familial support. Responsible, clinician-led support may serve as the basis for the development of self-agency, resiliency, self-advocacy, and self-actualization among these

children (Battles & Wiener, 2000; Brown, Lourie, & Maryland, 2000, Domek, 2006; Kindy-McPherson, 2005).

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