

Ethical Considerations for Prenatal Screening and Genetic Testing

Jennifer Ajandi, MSW, Ph.D.
University of Toronto

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Abstract

With the advancements made in medical technology, decisions that were once made with caution and information are now routinely handled in an automated fashion. When deconstructing the issues involved in prenatal genetic screening, we must ask, what are we screening *for*? This paper calls for social workers to play key roles as genetic counselors in health care settings.

Key Words: Prenatal screening, Genetic Testing, Genetic Counselors, Ethics, Disability Rights

Introduction

In this paper, I am exploring the practice of prenatal genetic screening. Specifically, I am analyzing the ethical implications to this particular kind of screening. I am using feminist (e.g., St. Denis, 2007), anti-oppression (e.g., Mullaly, 2002), and disability rights theories (e.g., Garland-Thomson, 1997) to critically analyze the effects of prenatal genetic screening for the populations involved. The literature I have reviewed includes articles from academic peer-reviewed journals as well as field notes I recorded during a social work placement in a health care setting at a large urban hospital in Ontario. I also reviewed the community-based agency, DisAbled Women's Network of Ontario (DAWN), which focuses on social justice issues as well as specifically the rights of women and girls with disabilities. I was able to access resources through the DAWN (2008) Web site regarding the balancing of reproductive rights for women with the decision to terminate a pregnancy that has had a fetus diagnosed with a disability (Rothman, 1986). Currently, the rapid rate of technology advances has stifled potential debate concerning prenatal screening for women. "With increased detection of congenital anomalies, more women and their families are faced with difficult choice" (Fertel & Reiss, 1997, p. 48). Policies need to be developed and implemented that involve promoting true informed choice for women. Community members and populations affected by potential policies, such as people with disabilities, need to be represented and involved in these processes.

Practicum Setting

While I was completing my graduate degree in social work, I was offered a practicum at a well-known urban health care setting in Ontario, Canada. The social work team provided services to women who experienced high-risk pregnancies, had premature babies born in, or transferred to, the Neonatal Intensive Care Unit (NICU), or to families who experienced perinatal loss. According to information from the United States, the birth of a baby is considered premature when the woman delivers between the 20th and 37th week of pregnancy (Bachman & Lind, 1997, p. 7). According to Preyde (2007), the criteria for categorizing an infant as premature or “very preterm” is that the baby is born at less than 30 weeks’ gestation or weighs less than 1500 grams (p. 70). This classification adds in the weight of the baby as a factor for determining her/his prematurity level. However, I would caution drawing any conclusions regarding what steps are taken to preserve life in the hospital, based on the number of gestational weeks alone. It is common practice, in the hospital where I did my practicum, not to encourage parents to resuscitate their babies if they are born under 24 gestation weeks. Whereas it is not expected a baby will survive if she/he is born before 24 weeks gestation, I have worked with families whose babies did. Conversely, I have worked with families who had babies born at older gestational ages who did not survive. Generally, at this hospital, we would see babies between 23 weeks’ gestation and 32 weeks’ gestation. In situations in which the baby is not expected to survive, the issue of when to withdraw or withhold treatment is contentious, as many times the decisions are made on an individual basis between the doctors and the families.

A pertinent issue in my placement setting was the process involved for women and their families when they were faced with the decision to terminate a pregnancy or request a withdrawal of care for their baby after she/he was born. In order to illustrate these experiences, I have drawn upon examples of current practices (both formal and informal) pertaining to women who undergo prenatal screening. What follows is a look at the difficult decisions women are faced with if they are informed of potential genetic complications with their fetus or child. I use the term “fetus” for before the birth, and “child” for after the birth, as genetic complications can be detected both in utero and after the birth. Most often, if a fetus or child is not expected to survive, this is referred to as being incompatible with life.

First, it is important to note the larger structural conditions that are occurring in Canada. Canada is known around the world as being a leader in providing accessible and affordable (or

“free”) health care for its citizens. It is true, that as a Canadian citizen, I am fortunate to not have to worry about whether I have enough money to pay for an appointment with a doctor if I get sick, because many traditional or Western health care services are insured under the provincial government. However, this does not mean the health care system is accessible to all. Many people in rural communities, especially Aboriginal peoples, are underserved or served poorly by our health care system (Bourassa, McKay-McNabb, & Hampton, 2006).

Health care in Canada, specifically in Ontario, has experienced drastic cuts to its funding. The restructuring of the health care system has led to the privatization of many services that were once insured under the Ontario Health Insurance Plan (OHIP) (Bezanson, 2006). A reduction in funding also contributes to reducing the number of staff. However, the amount of work does not decrease. Health care staff experience unrealistic workloads, and this can also be felt by social workers. With more work to do and fewer people to do it, health care settings can be stressful places to work. Social workers begin their days with an idea of what to expect according to their schedules. Their “schedules” change several times throughout the day because of the crisis nature of their work. For example, a social worker may have appointments with three different families who need information and various resources to assist them in feeling prepared for when they are discharged from the hospital. However, in the event of a baby’s death or if the health of a baby declines, those babies’ families become top priority, and all other appointments are rescheduled accordingly. The role of the perinatal social worker fluctuates depending on the current crisis at hand. Perinatal social workers at the hospital where I did my practicum also needed to work in several departments concurrently, because they were understaffed. There are several reasons why patients are referred to social workers. They can include: mental health issues, lack of housing/under housing, poverty, substance use, intimate partner violence, stillbirth, miscarriage, parenting concerns, child protection issues, and the diagnosis of a child or fetus with genetic anomalies or with being incompatible with life.

Critical Appraisal of the Literature

In this paper, the right to self-determination of women regarding their reproductive health and bodies is not put up for debate. As a single mother, I find many strengths and advantages to this status. However, I have also endured several challenges. I learn to cope with the stress associated with being poverty-class, balancing school with paid work, unpaid work, and the new role of motherhood. Being able to go through these experiences has only enhanced my passionate

belief that women must have control over their reproduction. This not only includes the right to terminate pregnancy, but also the right to continue a pregnancy, as many women of colour, Aboriginal women, women with disabilities, and poor women have had to fight for. On a professional level, self-determination is mandated in our *Code of Ethics*. Social workers are guided to respect the dignity and self-determination of all of our clients/service users/patients (CASW, 2005).

To explore the tensions around prenatal screening, we must first look at how power and knowledge are created and then reproduced. I am deconstructing the production of knowledge using a critical lens informed by feminist, anti-oppressive, and neo-colonial theories. With respect to the development of the medical profession, I am also using perspectives informed by the social model of disability, which locates the roots of problems in a society that creates ableist structures, as opposed to locating the problem in the disability itself (Oliver, 1990). According to Smith (2005), Western, scientific thought has developed in support of modernism (p. 59). Modernism represents a particular stream of thought that views facts and truth in society as being objective, measurable, and controllable (Hugman, 2003; Mullaly, 2002). The medical profession has grown out of a primarily white, male, able-bodied construction of scientific knowledge and reason. This began with the era of Enlightenment, in which objective “expert” knowledge emerged as the dominant form of treatment (Boetzkes, 2001). The physical body itself is objectified, pathologized, and examined/diagnosed in terms of “normal” and “abnormal.” By using these dichotomous phrasings such as healthy/unhealthy, male/female, and able/disabled, there is little room for variations of the body represented on a continuum. This modernist ideology is still present in many hospital settings as well as in streams of different helping professions, such as psychiatry, psychology, and social work. Social workers must be cognizant of ethical guidelines that we are to do no harm (CASW, 2005). What does this mean, and what does the current knowledge and practice say about issues in society? It is just as important that we in the helping professions critique our own practices. It was not too long ago that “women were frequently counseled to calm down and return to abusive situations, and they, rather than the perpetrator, were often defined as the problem” (Hill, Glaser, & Harden, 1998, p. 105).

Individuals are still labeled as the problem. For example, in a multi-disciplinary meeting in the health care setting, one of the families assigned to me had an infant girl who some of the nurses brought up may have additional male body characteristics. There was an obvious tension in

the room as nurses and neonatologists discussed sending the baby to the local specialized hospital for genetic “abnormality” testing or to the “dysmorphology clinic.” The staff was debating what direction to take, so as a point of clarification, I asked if the baby was intersex. I used the category/identity intersex out of respect for children born with various gender and sex identities and as a way to verbally normalize this body against the deficit model being espoused in the room I was in. The production of modernist knowledge needs to be challenged for attempting to maintain dichotomous categories of the body (Garland-Thomson, 1997). I received no response from the health care team—just an awkward silence. I found this lack of response problematic, considering I was a colleague. How would medical staff interact with families regarding sensitive issues such as these if they could not even address me? Although there has been much resistance to reducing the power differential between patient and professional, in theory, community-based care, interprofessional care and patient-centered care is the current trend being supported in health care settings in Canada (New Health Professionals Network, 2005).

Genetic ethics is emerging as an important discourse with the advancing of medical technology at increasingly rapid rates; however, public discussion and debates seem to lag far behind. Implicit in different types of knowledge are underlying sexist, racist, and ableist assumptions. We can see racism highlighted from the push to “immunize” against fertility in the “Third World,” sexist assumptions that contributed to the pathologizing of menstruation, and performing hysterectomies to prevent menopause (Boetzkes, 2001). It is realistic and appropriate then that consumers and professionals alike question dominant discourses put forth within the medical profession.

Informed Consent for Prenatal Screening

According to Garcia, Timmermans, and van Leeuwen (2007, p. 754), “In many countries prenatal screening has become normal antenatal care.” When prenatal screening becomes routine during antenatal care, does informed consent cease to exist? Informed consent is an important process that social workers and allied health professionals use both ideologically and legally when providing services. However, as professionals and in different disciplines, each person may enter into these processes with varying intentions. In terms of prenatal screening, Boetzkes (2001) argues that women need to be “maximally informed” (p. 304), but what does this mean? In Canada, social workers follow the Canadian Association of Social Workers’ (CASW) *Code of Ethics*. However, it was not until Ontario implemented the Social Worker and Social Service Work Act

1998 that social work as a profession became regulated. Regardless of the degree obtained, social workers in Ontario cannot use the title “social worker” unless they are registered with the Ontario College of Social Workers and Social Service Workers (OCSWSSW, 2008a). There are many ethical considerations social workers are obligated to adhere to in the OCSWSSW’s *Code of Ethics* pertaining to women and prenatal genetic screening. They include confidentiality, a right to information, to be informed of foreseeable risks, and to have the social worker serve as an advocate for clients (OCSWSSW, 2008b). It is also important to note that the right a client has to confidentiality is balanced with a social worker’s duty to report a situation to authorities if a client threatens to harm her/himself or someone else (Mishna, Regehr, & Antle, 2003), and especially in Canada, if the person is a child under the age of 16 (Lundy, 2004, p. 101).

Kohut, Dewey, and Love (2002) consider informed choice “as a process of decision-making, which evolves through the evaluation of information and personal values related to testing” (p. 266). This is different from informed consent. Informed consent is a legal category that is requested from the doctor in order to perform a medical intervention, whereas informed choice involves all of the background knowledge and information to specific medical interventions. Lundy (2004) emphasizes the importance for social workers to obtain informed consent in their practice, according to the *Code of Ethics* in both Canada and the United States (p. 96). Informed consent is meant to be a process in which all information pertaining to a procedure is discussed between the patient and the health care staff. Furthermore, according to the Canadian Tri-Council Policy Statement (2008), informed consent is mandatory and at the heart of ethics in research, designed to protect participants. In the United States the language of the policies governing informed consent appears to be more stringent and may be in response to the threat of litigation. It is stressed that complete and accurate information must be given in order to obtain informed consent, or it is not valid (United States Department of Health and Human Services, 2008). Also, according to informed consent policies in the United States, it is strongly advised that consent be obtained in writing, whereas in Canada, the policies have given explicit accommodation to cultural groups that may communicate informed consent orally or by a handshake (Tri-Council Policy Statement, 2008). Whether health care staff uses the notion of informed consent or informed choice, there needs to be an organizational and cultural shift toward a less paternalistic approach of interacting with patients. Instead of doctors and other helping professionals being seen as the “experts,” patients need to be given time to be involved in the actual process of information

gathering and then be able to process this knowledge for the purpose of decision-making (Kohut et al, 2002).

“Choice”

Currently, there is a prevailing cultural story present within the institution of health care. It involves scientific merit and diagnostic ability (Truog, 1996). With the advances in medicine and technology, it can be argued that women’s choices surrounding issues of reproductive health are also increasing. However, “choice” is a contentious issue. Does a woman have reproductive choice if she wants to keep her baby but fears the economic disadvantages she will experience if the baby is diagnosed with a disability? Choice is contextual as an example from my placement setting will make clear; women most often take the recommendations of the doctor or will pick up on the doctor’s tone, which helps to sway the decision one way or the other, independent of other valid sources of information or concern. Truog (1996) maintains that an informed choice can only be made if women receive all the information relevant to the decision to undergo or forgo the test and feel free of coercion or persuasion.

Women are overwhelmingly represented in the highly stressful primary caregiver role. These stresses are compounded when women experience poverty. The decision to give birth to a child who will be diagnosed with having disabilities is especially difficult if the family does not have sufficient economic and emotional resources available. Unfortunately, this issue is exacerbated when taking into account that the caregiver role is seen as an operation in the private sphere (predominantly by women) with little or no systemic supports (Mullaly, 2002). However, even women who are financially secure may have second thoughts when faced with the possibility of having a child with disabilities, as there is a fear of who will care for the children after the parents die (Boetzkes, 2001).

When women make the decision not to have prenatal testing, they may be looked at as selfish or uncaring. If her child is born with a disability, some members of society blame the mother, because it is expected that if she were a loving and caring mother, she would have “prevented this tragedy.” There is a dominant hegemonic assumption of what a good quality of life looks like. In the United States, there are cases in which insurance companies refuse to insure the health care of a child with disabilities if it is known the disability could have been prevented (Harmon, 2005). In a study conducted in the Netherlands, pregnant women were asked their reasons for accepting or declining the offer for prenatal screening. In the Netherlands, prenatal

screening is not a part of routine prenatal care. Most of the participants who decided on having the prenatal screening did not feel they could raise a child with disabilities. Some reported they desired a life of “normalcy” and feared how society would view them and their families. However, “All participants worried about the obsession with physical perfection in society. They feared that prenatal testing would be used as a eugenic means, leading to the commodification of children” (Garcia, Timmermans, & van Leeuwen, 2007).

In a study conducted in Ontario, focus groups were used to elicit information from women regarding their experiences of prenatal screening (Carroll, Brown, Reid, & Pugh, 2001). It is clear that the participants were assumed to know what the screening was without being fully informed. Participants also expressed concern for whether they would have the resources to be able to support a child with disabilities if the screening results were positive for “genetic anomalies.” An important discussion in this study focuses on the need to have counselling before the tests are actually performed (Carroll et al., 2001).

Ethical Issues

As prenatal genetic testing is ever expanding, there are legal, ethical, medical, and social concerns that need to be considered. Genetics research has serious implications for communities. Because the outcomes of specific testing may serve to further marginalize or discriminate against an already vulnerable group of people, communities and the public need to be a part of the policy making process. People who have genetic conditions may feel isolated and not valued in society when there are specific tests made available to detect their conditions and these most often result in termination of the pregnancy. The head of self-advocacy for the National Down Syndrome Society describes feeling a “child” when thinking of genetic testing that is done to remove lives like her own (Harmon, 2005, p. 1). This is especially relevant when taking into account a disability rights perspective, which explores how disability should be seen on a continuum as various kinds of people with different abilities, just as there is a range in eye and skin colour in human variation. It is advocated that disability be seen as a human rights issue, not a medical one (Devaney, 2008).

Policies regarding prenatal testing—when to offer it and to whom, and the explanations that are given pertaining to that disability—are usually done by professionals, unrepresentative charities and governments, not by the people who have disabilities themselves, who are the best experts on their own lives (Gollust, Apse, Fuller, Miller, & Biesecker, 2005). An important concern around prenatal screening is that it reinforces the medical model standpoint – that

disability is the problem – instead of focusing on strategies to dismantle societal discrimination toward people with disabilities (Parens & Asch, 1999). Research shows health care staff view the increasing occurrence of prenatal genetic screening and conditions to be screened for as inevitable (Williams, Alderson, & Farsides, 2002). Currently, there is little room for collaboration and debate regarding the ethics involved with prenatal genetic screening, and medical advances are increasing at a rapid rate. Williams et al. (2002) argues for:

inclusive, integrated and collaborative debate and research. This is to ensure that as far as possible the wider consequences and implications of prenatal screening technologies – both the promises and the potential side-effects – are debated ahead of their implementation, and also to help ensure that public policy represents and serves contemporary society. (p. 752)

Surveying Women

There are ethical implications involved when going through the decision-making process around whether to terminate a pregnancy if it is diagnosed the child will be born with disabilities. These include the current biomedical model that pathologizes disabilities, skewing the picture because of a lack of information surrounding a strengths perspective of disabilities or, at the very least, information from a community member point of view. For example, using surveys with people who are affected with inherited “dwarfism” highlights the experiences of this population from their own perspectives. These data have been used in policy development, as well as clinical practice contexts (Gollust et al., 2005).

Research has found that surveys are good tools because they can reach a large number of people in a short period of time. Surveys that are accessible online can also increase the likelihood of a more geographically diverse pool of women participating. Surveys that have large sample sizes, averaging 1000 people, enable the researcher to highlight certain trends that emerge from the data. This can then serve as the basis for further research into a specific area through such means as qualitative open-ended and semi-structured interviews with women, providing a more experiential and complex perspective on prenatal screening in health care settings. Results from a recent study showed that women preferred face-to-face genetics counselling with a mix of knowledgeable printed material. Also highlighted was the desire to connect with other women who decided to undergo prenatal testing, suggesting that a support group may be beneficial (Jacques, Bell, Watson, & Halliday, 2004).

When advocating for policy changes or implementation, having such a large representative sample carries some political weight. However, a limitation to using self-report surveys is that it is not possible to capture the complexities of individuals' lives, which is where qualitative research can play an important role. For example, in a study of 120 women who underwent amniocentesis and received a diagnosis of disability for the child, all women decided to terminate the pregnancy. Rothman (1986) describes with empathy the pressures these women experienced and constructs them as victims of technology, sacrificing themselves to spare their children from suffering.

Researchers need to take into account different models of health care service and delivery when analyzing their data. In one study, data was collected from women who received prenatal care from an obstetrician and a midwife. The results were highlighted that more than half of the women made decisions regarding prenatal screening without true informed consent. It seems a contradiction when the medical intervention of prenatal screening was designed for the purpose of enhancing informed consent regarding the health of the fetus (Van den berg, Timmermans, ten Kate, van Vugt, & van der wal, 2006). It would be beneficial to do a comparison study involving informed choice or consent between women who were involved with midwives compared with obstetricians. It is important in the research to distinguish between these health care providers, as both operate within a completely different ideological framework, and therefore these different theoretical frameworks of care will influence the experience of the patient.

Implications for Practice

There is a clear gap in the literature around social work's role with patients who consider genetic testing and more specifically prenatal genetic screening. In existing literature social work interventions are seen as of major importance. However, it is almost completely absent from professional writing (Gagin, Oded, Cohen, & Itskovitz, 2001). As this is a new and emerging focus within the health care setting, it would be beneficial for the field of social work to develop a genetics specialization within the health care stream. In the United States, the National Association of Social Workers' *Code of Ethics* emphasizes guidelines that support social workers in the field of genetics including self-determination, informed consent, and social and political action (Taylor-Brown & Johnson, 1998).

The role of a genetics social worker, given the expansive knowledge base, is vast and complex. It involves emphasizing a focus on values and ethics, social policy in genetics, ongoing counseling for coping and adaptation, identifying clients with potential genetic disorders through

case-finding and bio-psychosocial assessment, knowledge of the person in environment paradigm, and biological knowledge, specifically with the Human Genome Project (Taylor-Brown & Johnson, 1998). This in addition to the already varied roles of social workers in health care settings presents quite a challenge. An important aspect of a social work role in genetics would be identifying the alternative resources (and lack of alternative resources) available to patients. Public involvement into genetic policymaking is recommended in the literature, and similarly, from community members, although the norm is currently not to include a community voice (Mattison, 2000). A vital role for social workers in this field will be to provide that information and documentation. Are patients given information and research that supports not only negative quality of life outcomes but also positive outcomes for families who have children with disabilities as well? Is empirical data available that describes individuals' quality of life through participatory research? Callahan (2004) emphasizes the role of feminist thinking in policy making. There is relevance for learning from the everyday experiences of women and the particular challenges they face in order to construct a bottom-up approach to policy development and implementation. This is important as the process of marginalization works in a way to exclude whole groups of people from meaningful participation in society (Mullaly, 2002).

Based on the reviewed literature and systematic studies, I conclude that women are not provided with genetics and options counseling and, in effect, do not have sufficient information to properly undertake the process of decision-making for prenatal screening. However, the Ethics and Public Policy Committee of the Canadian College of Medical Geneticists supports women's right to autonomy and right to informed decision making regarding prenatal interventions (Kohut et al., 2002). Prenatal genetic testing is highlighted in this paper as a rapidly emerging field in medicine. The implications of scientific and technological advancements in medicine need to be publicly debated and/or a dialogue created so voices can have a platform where marginalized discourses are heard.

Proposed Evidence-Based Interventions and Policy

In our role as social workers, we must continuously use reflexive practice, so as to question our values and assumptions. We cannot take ourselves out of the equation when counseling and providing services. It is important to recognize that our actions are framed by our beliefs and how we view the organization of our society (Mattison, 2000). By constantly reflecting on and questioning our motivations in practice, it is more likely we will be able to start with the

client/patient where s/he is, instead of where we are. Furthermore, I would suggest that it is important for the profession to deconstruct the dominant societal discourse and messages as these greatly influence our own perceptions and ideology, directly influencing how we practice and, most significantly, narrowing or distorting client choices.

Through the review and analysis of field notes during my graduate practicum, it has become clear that it is a moral imperative to reflect on these ethical issues. Moreover, this experience has instilled in me a desire to teach university courses in ethics and values. I shall address some ways to address these issues in a multi-pronged fashion. First, on a macro and institutional level, participation of people who belong to marginalized groups such as persons with disabilities must be involved and represented at all policy levels. It is time that the policy making process shift its direction from a paternalistic top-down approach, to incorporate minority and advocate voices. The dominant paradigm in medical institutions is the medical model. This paradigm views the body based on a deficits model, examining the person in terms of disease and treatment, instead of validating strengths and human variations (Graybeal, 2001). Creating change and shifting organizational culture is a slow process. One of the ways to help facilitate this is to infiltrate the education system. Besides the family, educational institutions are one of the first organizations that contribute to the socialization of people and professions. There needs to be a challenge to dominant discourses such as the medical model. Incorporating the social model of disability would present a view that is not biodeterministic. Thus, it would recognize a social-determinants-of-health perspective that deconstructs structural inequalities, locating the problem with systemic issues, not the individual person.

On a direct practice level, employing a social worker specializing in genetics would be an important step in being able to present information to the patient regarding her choices. When adequate information is not present, social workers could connect patients with key members in the community who would act as education liaisons. These education liaisons would offer perspectives not necessarily influenced by the medical model to balance the ideological context of the information given to the patient in the hospital. Another aspect of this kind of genetics/ethical counselling would be in the support work that may be required after the woman has made a decision regarding prenatal screening, either counselling after termination or connecting to appropriate resources if continuing with the pregnancy.

Social workers could use their skills with facilitating groups. An ad hoc session for women considering their options for prenatal screening and/or termination could be explored to reduce isolation and feelings of confusion or guilt. However, in group situations, it is difficult to ensure the emotional safety of group members especially considering the subject of discussion.

Strengths and Limitations for a Genetics Social Worker

Unfortunately, it is unrealistic to envision departments of social work expanding in hospitals, considering the increased cuts to health care. The strongest limitation for having a genetics social worker in perinatal departments may be purely based on a lack of resources and funding. Also, even though the concept of true (i.e., meaningful) informed consent could be challenged by a social worker, the medical staff might not be receptive to that kind of criticism, so the actual lack of staff support may be an additional barrier. Furthermore, if disability continues to be viewed as pathology and “dysmorphic,” there may be an unwillingness to reconceptualize disability as a healthy variation of people, as some people with disabilities contend.

Working toward social justice for marginalized populations is at the core of the profession of social work and codified in our ethical guidelines (Lundy, 2004). Working in secondary settings often requires us to be mediators, educators, advocates, and allies. We skillfully challenge the dominant discourse when we see it to be oppressing patients with whom we work. I argue we need to develop a strategy to implement a new role for social workers and suggest that we use our interests and skills in research to develop a proposal that would support prenatal genetic counselling. This is an exciting opportunity for social workers to highlight our wide scope of practice for the benefit of some of the most vulnerable clients served by our profession.

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