Who's In and Who's Out? The Ethics of Excluding Language Minorities in Social Work Research

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Abstract

The percentage of non-native English speaking individuals in the United States is growing and is predicted to continue to grow for the foreseeable future. Between 1990 and 2013, the number of people in the United States who are described as Limited English Proficient grew by 80%, with the number of individuals unable to speak English fluently in 2013 reported at approximately 25 million (Zong & Batalova, 2015; U.S. Census Bureau, 2013). By 2020, the number of Spanish speakers alone in the United States is predicted to rise to between 39-43 million (Lopez & Gonzalez-Barrera, 2013).

Despite their growing numbers within the population, language minorities—individuals whose native language is not English—continue to be excluded from research. Because research findings influence the systems and structures within our society by informing policy-making, program development, and public opinion, it is critical that research efforts include the diversity of individuals that make up our society. When groups within society are systematically excluded from participating in research, both the individuals within those groups and society as a whole are negatively affected through misleading results and ineffective policies and programs. From a social work perspective, this systematic exclusion of language minorities becomes a question of ethics when we consider the issue in relation to the NASW Code of Ethics, which provides standards for ethical behavior in both research and practice.

This paper seeks to describe the problem of excluding language minorities from research, examine the issue from two opposing ethical perspectives, and offer possible solutions.

Keywords: ethics, language minorities, research, exclusion/inclusion

Problem Description

The percentage of non-native English speaking individuals in the United States is growing and is predicted to continue to grow for the foreseeable future. According the Migration Policy Institute, the number of people in the United States who are described as Limited English Proficient grew by 80% from 1990-2013 (Zong & Batalova, 2015). In 2013, the number of individuals in the U.S. who described themselves as being unable to speak English fluently was approximately 25 million (U.S. Census Bureau, 2013). By 2020, the number of Spanish speakers alone is predicted to rise to between 39-43 million (Lopez & Gonzalez-Barrera, 2013).

Despite these staggering statistics, a 2016 systematic review of 58 random-controlled trials for Type 2 diabetes found that half of the RCTs used "English language proficiency" as a screening tool, and only 3 studies provided a rationale for this exclusion criterion (Isaacs, Hunt, Ward, Rooshenas, & Edwards, 2016). An earlier review of 212 studies of provider-patient relations found that only 22% included non-native English speaking persons

(Frayne, Burns, Hardt, Rosen, & Moskowitz, 1996). The primary reason given for the exclusion was that they had not considered the issue (Frayne et al., 1996). A report compiled by the National Institute on Aging identified cost as the primary barrier to including language minorities in research (Li, McCardle, Clark, Kinsella, & Berch, 2001). "Geographic distribution, language change over time, lack of coherence with research goals, and the use of community members as translators and interpreters" were identified as additional barriers (Li et al., 2001, p. 9).

In 1993, the National Institutes of Health Revitalization Act was created to ensure inclusion of minorities in federally-funded research. Despite these national-level policies, a 2015 systematic review of federally-funded studies found that inclusion of racial or ethnic minorities was found in only 5% of NIH-funded studies of respiratory disease (Burchard, Oh, Foreman, & Celedón, 2015). It is apparent that this gap in the representation of ethnic minorities (language minorities being a subset of this group) in many areas of research persists, particularly with regard to clinical trials. This gap has been argued to be a contributing factor to growing disparities in physical and mental health outcomes in the United States (Flores et al., 2002).

Target Population

The target population impacted by this issue includes language minorities—individuals for whom English is not their native language—living in the United States; however, the problem also impacts social work practitioners and their work with clients because it determines the evidence that is made available to them. Approximately 64% of the language minority population in the U.S. are Spanish speakers; 6% speak Chinese; 3% speak Vietnamese, 2% speak Korean; and 2% speak Tagalog (Zong & Batalova, 2015). Because language minorities make up a significant subset of the ethnic minority population, particularly the growing Hispanic population, and are more likely to live in poverty (Zong & Batalova, 2015), this problem should be a concern for social workers and the profession as a whole.

Purpose

The purpose of this paper is to provide a thorough description of the issue of the exclusion of language-minorities from research studies, the factors contributing to this problem and the consequences that may arise at a variety of levels as a result. The author will also utilize two divergent ethical perspectives on the issue in order to provide a framework from which to analyze and consider ethical action. In short, this paper will examine, from opposing perspectives, the ethics surrounding the decisions that researchers make regarding who they will study, the justifications given for these decisions, the consequences of these decisions for research and society, and possible solutions to the problem.

Ethical Issues

In order to understand the ethical problem being addressed, it is first necessary to identify the ethical issues that are raised. The clear articulation of the issues at hand allows us to use ethical decision-making frameworks that enable the researcher to weigh the relative importance of the principles underlying these issues and make choices that are rational rather than reactionary. Because social work researchers are bound by the National Association of Social Workers (NASW) Code of Ethics (2017) as well as ethical guidelines specific to research, such as the Belmont Report, both will be referenced in this paper. The Ethical Rules Screen and Ethical Principles Screen developed by Dolgoff, Harrington, and Lowenberg (2012) will be utilized as a tool to rank conflicting ethical principles.

NASW Code of Ethics

The Ethical Rules Screen indicates that social workers must first reference the NASW Code of Ethics when faced with ethical issues (Dolgoff et al., 2012). When we look to the Code for guidance, there are no rules that specifically refer to including or excluding subjects from research. In fact, the "Evaluation and Research" section of the Code focuses solely on protecting subjects from harm in research (NASW, 2017). They require the researcher

to "follow guidelines developed for the protection of evaluation and research participants" (NASW, 2017, p. 27). The Code goes into great detail about guarding against coercion of participants and taking steps to gain informed consent through thorough and complete disclosure of the risks and benefits of participation. These codes specific to research only address ethical behavior towards research participants once they have been chosen as study subjects; they provide no guidance with regard to the inclusion or exclusion of study subjects.

Though the NASW Code of Ethics does not provide specific guidance with regard to the issue of inclusion/exclusion of study subjects, researchers may then look to the Ethical Principles outlined in the Code in an effort to ensure that social work research reflects the same values as the profession as a whole. Of the six social work principles outlined in the Code, those that are identified as most relevant to the issue at hand are those of social justice and competence. With regard to the principle of social justice, the NASW Code of Ethics states, "Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people" (NASW, 2017, p. 5). Seen through the lens of the social justice principle, a lack of access to participation in research for language minorities reflects inequality of opportunity and, thus, may be seen as a form of discrimination.

The social work principle of competence holds relevance for this issue if we consider the consequences of exclusion of a particular group from research for the knowledge base available to the profession as a whole. The competence principle states, "Social workers should aspire to contribute to the knowledge base of the profession" (NASW, 2017, p. 6). If social work researchers should be held to the same principle as social work practitioners, it may be argued that the gap in professional knowledge that results from the exclusion of language minorities negatively affects the level of competence of the entire profession.

Ethical Principles Screen

Though the ethical principles outlined in the NASW Code of Ethics describe what is of value to the profession, there is no guidance with regard to the relative importance of each for ethical decision making. For this reason, it is helpful to utilize the Ethical Principles Screen to identify the relevant principles and weigh their respective value for social work. The Ethical Principles Screen identifies seven principles that are at play in any ethical dilemma and ranks them in order of importance: Principle 1: Protection of Life; Principle 2: Equality and Inequality; Principle 3: Autonomy and Freedom; Principle 4: Least Harm; Principle 5: Quality of Life; Principle 6: Privacy and Confidentiality; and Principle 7: Truthfulness and Full Disclosure. The principles that are relevant to the identified problem and that will be discussed in this paper are Principle 2: Equality and Inequality and Principle 3: Autonomy and Freedom (Dolgoff et al., 2012).

The principle of equality and inequality relates to the issue of inclusion/exclusion of study subjects because the level of knowledge that is gained from research and made available to practitioners will be more accurate and representative of particular populations and may be inaccurate or incomplete for others who have been excluded. In the past, there has been concern that minority groups have unfairly borne the burden of research without enjoying the benefits. However, protections that are now in place to guard against exploitation of human subjects may place undue burden on researchers, and this burden contributes to unequal representation of language minorities in research studies. Thus, equality must be examined in terms of both burdens and benefits of participation for human subjects.

The principle of autonomy and freedom should be considered in relation to this ethical issue as well. When researchers exclude language minorities from research studies for reasons based on convenience, budget, or logistics, it could be argued that the researcher is then robbing an entire segment of the population of their autonomy and freedom to choose to participate. Autonomy is often

thought of in relation to consent and ensuring that participants do not feel coerced into participation. However, the concept is rarely considered in relation to the decisions that researchers make in setting inclusion/exclusion criteria. From this perspective, it is equally important for an individual to have the freedom to participate as it is for them to have the right to decline participation.

The Belmont Report

Outside of social work, there are also guidelines that have been established to promote ethical research practices and guard against abuses. One such guideline is the Belmont Report, which was written in response to the uncovering of the abuses perpetrated against African-American study subjects in the Tuskegee Syphilis Study (Department of Health, Education, and Welfare, 1979). Because these guidelines were developed in response to serious and egregious violations of basic human rights in the name of science, they tend to be conservative in nature and focus on the protection of individual study subjects.

The Belmont Report highlights three core principles for ethical research practice: respect for persons, beneficence, and justice (DHEW, 1979). The principle of justice is particularly relevant to the issue of study subject selection in that it addresses the question of "who ought to receive the benefits of research and bear its burdens?" Though this section begins by stating that research involves both benefits and burdens for participants, the majority of the report focuses on the conceptualization of research as a burdensome activity.

Later in the report, the authors specifically address the issue of subject selection in relation to the core principle of justice at both the social and individual level (DHEW, 1979). They state that, at the individual level, researchers "should not offer potentially beneficial research to patients who are in their favor or select only undesirable persons for risky research" (DHEW, 1979, Selection of Subjects section, para. 2). At the social level, the report points out that injustice may occur, despite fair selection procedures on the part of the researcher, due to

institutionalized biases that exist in society. The report categorizes racial minorities, which would include language minorities, as vulnerable subjects, who are characterized as having a dependent status and a compromised capacity for free consent (DHEW, 1979). The basis for this categorization is unclear, but it may serve a discriminatory function if it encourages systematic exclusion of a population group from research participation.

Because the Belmont Report focuses primarily on the protection of human subjects from research abuses and does not explicitly address the inclusion/exclusion of language minorities, some Institutional Review Boards (IRB) have found it necessary to interpret the principle of justice in order to provide some guidance for researchers under their authority. For example, section 4.5 of the 2017 protocol submission guidelines developed by the IRB at University Hospitals in Cleveland, Ohio not only requires researchers to provide a precise definition of the population to be studied, but goes further to state: "Part of subject selection includes ensuring that no person is unduly denied access to research from which they could potentially benefit, without good reason (Belmont Report, ethical principle of Justice)" (University Hospitals, 2017, p. 3). The next statement in section 4.5 goes so far as to provide direction specific to the issue of the inclusion/exclusion of non-English speaking persons in research and addresses two of the most commonly-reported justifications for exclusion: "For example, excluding non-English speaking individuals purely because it is inconvenient to have the consent form translated into an understandable language, or because the research staff does not speak the language is not an acceptable reason for exclusion" (University Hospitals, 2017, p. 3). The type of explicit language utilized by the University Hospitals IRB should be considered a best practice to be followed by both university and organizational review boards across the country.

Ethical Analysis

Utilizing the core principles identified in the previous section, we will now look to ethical

theories for guidance in resolving the issue of inclusion/exclusion of language minorities in research studies. Various ethical theories have been developed over the centuries, from Socrates to Rawls, in order to answer the timeless question, "What is right action and how do we decide what is right action?" In order to make a decision that can be justified, it is necessary to articulate the ethical theory that forms the basis of that decision. The following section will present an analysis of the issue from the perspective of two contrasting ethical theories: utilitarianism and deontology.

Voluntary versus involuntary acts

However, before we enter into such an analysis, it is necessary to address the concept of voluntary versus involuntary acts. In *Summa Theologiae*, Saint Thomas Aquinas (1948/1485) argues that knowledge is a prerequisite for an act to be deemed voluntary. However, he also emphasized that lack of knowledge does not necessarily mean that an act should be considered involuntary. In order to determine the voluntary or involuntary nature of the act, we must also examine the power of choice. If an individual is ignorant because he/she does not take the proper steps to obtain knowledge that is available, this is considered consequent ignorance; the act that results from consequent ignorance would, therefore, be determined to be a voluntary act of will.

This distinction is critical for the discussion of the issue at hand when we consider that, in the study by Frayne et al. (1996), over half of the medical researchers who had reported excluding non-English speakers from their study said that they had not considered the issue when designing and implementing their study. If we take into account that the National Institutes of Health Revitalization Act was enacted in March of 1994 and declared that women and minority groups and their subpopulations, which would include language minorities, must be included in NIH-supported research, we can consider the reason provided by the researchers in the Frayne study to be a case of consequent ignorance; therefore, the decision on the part of these researchers to exclude

non-English-speakers would be considered a voluntary act on the part of the researchers.

The claim of ignorance becomes even less justifiable given policy developments over the last twenty years. An Executive Order was issued by President Clinton in 2000, which was aimed at improving access for Limited English Proficiency individuals under Title VI of the Civil Rights Act of 1964 (Bustillos, 2009). More specific guidelines established in 2003 by the DHHS Office of Civil Rights further outlined requirements that individuals should not be excluded from participation in programs that receive federal funding based on criteria including LEP status, which was subsumed under national origin (Bustillos, 2009). Because these policies are now well-established and should be required knowledge for all researchers, claims of ignorance can no longer be used as justification. Therefore, for the purposes of the current analysis, exclusion of language minorities for any reason will be considered a voluntary act on the part of the researcher.

Utilitarianism

Utilitarianism is an approach to ethical decision-making that emphasizes the value of promoting the greatest good for the greatest number of people. Bentham suggested that determining the right action could be simplified to a type of mathematical equation in which "one would add up all the possible pleasure an action would bring and then subtract the amount of unhappiness the action would bring" (Freeman, 2000, p. 51). Therefore, utilizing this perspective requires one to predict the outcome of competing choices of action and choose the act that will bring about the greatest good to the greatest number.

We will now walk through the steps of the decision-making process from the point of view of the decision-maker, in this case the Principal Investigator (PI) on the research study, who must decide the inclusion/exclusion criteria for their study. Because one of the main responsibilities of the PI is to manage the resources of the project, the efficient and effective use of those resources

must be taken into account when making decisions. Typically, when a study is funded there is a fixed amount of money given over a specified amount of time, and the PI is responsible for making sure that the project reaches its goals while staying within that budget.

Set against this contextual background, we can look at the setting of exclusion/inclusion criteria as an aspect of resource allocation. From a utilitarian perspective, the desire to complete the most scientifically rigorous study possible with the designated funds would likely guide the setting of exclusion/inclusion criteria. In fact, Meinert (1999) compared two RCT studies with different ethnic and gender mixes and found that the inclusion of women and minorities almost doubled the cost of the clinical trial. The cost involved in including language minorities is perhaps the most significant of all population subgroups due to the need for translated materials, including consent forms and measurement instruments, and/or interpreters at various stages of the project. The increasing complexity of consent forms has resulted in increased translation costs, which multiply depending upon the number of language groups. For language minorities who are illiterate, in-person or telephone interpretation services may be necessary to gain informed consent.

Considering that most research budgets are fixed, spending on items that allow for the inclusion of language minorities often means sacrificing in other areas of the project. The outcome may be fewer staff employed on the project or fewer students to be sponsored by the project. It may mean that the sample size will be reduced, which often has an impact on the study design and/or analytical methods that can be used. If members of the research team had plans to publish the results of the study, the compromises to the study design may affect the type of journal that will publish the article.

From a utilitarian perspective, we can see that the exclusion of language minorities from a study may be justified by the disproportionate amount of the budget that would need to be spent on inclusion. In fact, regulations provided by the Department of Health and Human Services state that "the resources available to the grantee/recipient and costs" may be considered when determining "meaningful access" to federally funded programs for LEP individuals (U.S. Department of Health and Human Services, 2002, Section 5, Article 4). Therefore, from a utilitarian perspective, the strength of the argument for exclusion can be seen as directly related to the percentage of language minorities found in the target population of the study. A type of cost-benefit analysis would be performed for each language group and exclusion/inclusion decisions would be based on the size of the particular language group within the target population, the benefits for generalizability of results, and the costs associated with inclusion of that language group.

Deontology

Deontology is an ethical approach that was developed by Immanuel Kant and lies in direct opposition to the utilitarian approach discussed above. A deontological approach to ethical decision-making emphasizes the importance of using principles to guide action rather than determining the rightness of an action based on its potential outcome (Kant, 1963; 1785/1993). From a deontological point of view, the rightness of an action can only be judged on the basis of the intention of the actor. Kant believed that the only motivation that characterizes good intention is a sense of duty beyond the individual.

As we did using a utilitarian theoretical perspective, we will now walk through the decision-making process faced by the PI with regard to the inclusion of language minority subjects in the study. In contrast to our utilitarian researcher who utilized a cost-benefit analysis approach to making the decision, our deontological researcher will look to principles to guide this decision.

From a deontological perspective, the relevant values and principles that were identified in the NASW Code of Ethics and the Belmont Report would take priority. The principle of social justice found in the NASW Code of Ethics is similar to the principle of justice outlined in the Belmont Report.

The NASW principle highlights the duty of social workers to promote the right of individuals to have meaningful participation in decision-making. The systematic exclusion of language minorities from studies based solely on their language ability robs members of this population of the opportunity to make decisions that affect their life and further contributes to their marginalized status within the society.

Drawing on the NASW principle of competence, we can look at the decision to include language minorities as it relates to the duty of social work researchers to contribute to the knowledge base of the profession. The decision to exclude language minorities has the consequence of excluding an entire segment of the population, in many cases Hispanic/Latino groups, and these groups often comprise a significant portion of the client population served by social workers. In this way, social work researchers who choose to exclude language minorities are contributing to poor quality service on the part of social work practitioners and causing potential damage to clients who are not represented in research.

From a Kantian perspective, the difficulties posed by including language minorities, including additional time, manpower, and cost, are not sufficient justification for their exclusion. This conclusion holds true even if the burden is significant and results in making sacrifices in other important aspects of the project. It would also be considered unethical for a PI to choose research questions that will allow him/her to avoid addressing the issue by focusing on issues that would naturally exclude language minorities. Because the intention is based on self-interest, the resulting action would still be considered unethical from a deontological perspective.

Ultimately, in order to settle on a decision that could be considered ethical, the PI will need to ask, "Would I want this action that I choose to become a universal law?" In this particular case, "If I were a member of a language minority group that was part of the target population of the study, would I want the opportunity to be able to decide for myself if I participate or not?" It can be assumed, for the vast majority of people who value self-determination, that their answer would be that they would want to be presented with the opportunity, regardless of their language ability.

The value of a deontological perspective for social work research

Despite criticisms that deontology is too rigid and lacks the flexibility to address real-life problems, it is clearly the approach that aligns closest with the principles and values of the social work profession, particularly the values of social justice and the dignity and worth of the person. In fact, it could be argued that a shared adherence to a deontological approach to ethical decision-making based on the NASW core values is the ideal mechanism to unify the three major areas of the profession (practice, teaching, and research) moving forward. Utilizing a decision-making framework, such as utilitarianism, that focuses on providing the most good for the greatest number of people would be problematic for a profession, such as social work, that is dedicated to advocating for the needs of marginalized groups. Certainly, challenges such as limited funding and policy regulations make the implementation of deontological decision-making more difficult in practice; however, these challenges should not deter social work researchers from abiding by their principles and setting the standard for research with marginalized populations that will serve as a guide for other professions.

Implications for Social Work Research

The preamble of the NASW Code of Ethics (2017) states that social workers should "strive to end discrimination, oppression, poverty, and other forms of social injustice" through a wide variety of activities that include research and evaluation (p. 1). In our mission statement we are called to use research to end social injustice, which means that we must advocate for the fair representation of language minorities in all areas of research. Ignorance of the language minority communities

within target research populations is no longer an acceptable justification for exclusion.

Casado, Negi, and Hong (2012) have suggested strategies for social work research to conduct culturally-competent research with language minorities. However, it is not enough for each individual researcher to commit to ethical practice with regard to the inclusion of language minorities; this issue requires purposeful action at the national level of the profession in order to move from avoiding unethical practice to promoting social justice. Historically, guidelines regarding inclusion of minorities in research were written in reaction to abuses of power on the part of researchers; yet we must move past this view of minorities as "vulnerable populations" or we run the risk of perpetuating a different, yet still oppressive, form of discrimination. In order to support the ethical and just practice of individual social work researchers as they lead the call for the fair representation of language minorities in research, a three-part macro-level approach to addressing this ethical problem is outlined in the following section.

Code of Ethics for social work research

Though the NASW Code of Ethics touches on the area of research, inclusion and exclusion of study subjects and the justification for either choice is not discussed. The code highlights the importance of protecting the rights of study participants and points researchers to their appropriate institutional review boards for more specific guidelines. However, most institutional review boards do not address the issue of inclusion/exclusion of language minorities, and those that do tend to focus on protecting minorities from the burdens of research. For this reason, social work researchers must not be satisfied that simply adhering to the guidelines provided by their IRB ensures ethical research practice. Social work researchers must hold themselves to a higher standard grounded in their values and tying them to fellow social workers in the field.

In order to accomplish this goal, a code of ethics specific to social work research must be developed that addresses the issue of inclusion

from a social justice perspective. The code should articulate the ways in which research may be used as a tool of oppression and require social work researchers to take necessary steps to avoid these unethical practices. For example, purposefully choosing research questions that result in a sample that does not include language minorities in order to avoid addressing the issue should be identified as an unethical practice.

Social work journal requirements

The second part of this macro-level plan involves action on the part of social work journals, their editors and reviewers. Social work journals must make explicit the requirement that authors describe their exclusion/inclusion criteria in detail and provide an explanation for the exclusion of language minorities. Social work journal guidelines for authors must emphasize that studies that do not provide exclusion criteria or fail to provide adequate justification for exclusion of language minorities will not be accepted for publication. Because great emphasis is placed on the number of publications for hiring, promotion and tenure, this move would certainly be motivation for researchers to address this issue at the initial stages of designing their study.

Not only should studies that improperly exclude language minorities be rejected by social work journals, but studies that take the necessary steps to include language minorities should be recognized and awarded points by reviewers and editors. Editors should instruct reviewers to look for this component of the article and ask for clarification if this information is missing. In this way, social work journals will be reaffirming the values of the profession, helping to develop a depth and breadth of knowledge within the profession, and distinguishing social work from other fields based on our commitment to social justice.

Breaking down financial and legal barriers

It is important that we recognize that conducting research with language minorities involves a greater expenditure of resources than

research with English-speaking participants only. Acknowledging this reality, it is necessary that the profession create mechanisms for providing additional resources to accommodate this need. Research grants specifically designed to cover the additional costs of including language minorities should be offered by organizations such as the Society for Social Work Research. At the same time, social work researchers and their organizations must begin to gather evidence of the costs involved with the responsible inclusion of language minorities in research and advocate for appropriate levels of funding from major funders such as the National Institutes of Health. Efforts should also be made to share resources such as consent forms in multiple languages so that the burden of including language minorities will lessen over time.

Social work researchers must also advocate for the removal of the designation of minorities as "vulnerable populations" in the language of guidelines for ethical practice. Historically, this designation served a purpose in the protection of minority populations from being exploited in the name of research. However, this designation implies that minorities lack their own decision-making abilities and robs them of their dignity and right to self-determination in all aspects of their lives. It is time to remove this type of language from research guidelines and address the right to participation as much as we highlight the right to protection.

Conclusion

Though statistics show that the number of non-native English speaking individuals in the United States continues to grow, research practices have failed to change to accommodate this changing demographic. The unjustified exclusion of language minorities from research across a number of fields should be viewed as a social justice issue and a pressing ethical dilemma for those whose mission is to serve marginalized populations. For social work research in particular, ignoring a significant minority of the population in much of our research will certainly leave us at a disadvantage in serving our language-minority clients.

With the current political climate shifting towards greater exclusion of immigrants in many aspects of society and increasing threats to the funding of scientific research, it will, no doubt, become more challenging for social workers and social work researchers to call attention to unethical practices and advocate on behalf of the inclusion of language minorities in all areas of research. Despite these challenges, social work researchers must take the lead and move past the reliance on institutional review boards for guidance on ethical research practice. A comprehensive approach that involves policy changes at the national organizational level combined with individual and project-based efforts holds the most promise for addressing the issue. A clear articulation of the profession's stand on the inclusion of language minorities in research is necessary to ensure that the core values and mission of social work are reflected in our research practices and that social work research is serving to build a knowledge base that accurately reflects all parts of our diverse society.

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