RESEARCH AGENDA
HOMELESSNESS AND HEALTH CARE

Summary of Findings

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May 2005

The National Health Care for the Homeless Council is a membership organization comprised of agencies and individuals providing health care to homeless persons. The HCH Clinicians' Network is a component of the National Council.

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This project was supported by a grant from the Health Services and Resources Administration (HRSA). The views expressed herein do not necessarily reflect the views of HRSA.

TABLE OF CONTENTS

Acknowledgements 3

Executive Summary 4

Introduction 6
- Information Sources 6

Current Research Priorities 9
- Perceptions of Interviewees 9
- Literature Scan Findings 9

Future Research Directions 11
- Translate Research Into Practice 11
- Structural Causes of Homelessness 12
- Subpopulations 13
- Healthcare and Access 14
- Affect Policy 14

Improving Research and Overcoming Barriers 15
- Funding Sources and Strategies 15
- Framing the Research Question 17
- Methodological Issues 18
- Role of the National HCH Council & HCH Clinicians' Network 21

Next Steps 22

Appendices 23
- A: List of Interviewees 24
- B: Recruitment Letters 27

ACKNOWLEDGEMENTS

The following members of the National HCH Council/HCH Clinicians' Network Research Coordinating Committee were instrumental in the completion of this project. Their contributions included: crafting interview questions, editing drafts of recruitment letters, scheduling and conducting interviews, and assisting with this summary report. *(Note: Current members are indicated with an * beside their name.)*

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Members of the HCH Clinicians' Network Steering Committee and the National HCH Council Governing Members and staff also assisted in identifying interviewees and responding to this report.

Much of the content of this report has been gleaned from interviews with members and leaders from within the NHCHC and HCH Clinicians' Network, and with researchers and other professionals for their contribution to the field. A complete list of external interviewees can be found in Appendix A of this report.

EXECUTIVE SUMMARY

In early 2004, the Research Coordinating Committee of the National Health Care for the Homeless (HCH) Council and HCH Clinicians' Network launched an effort to develop an agenda for future research on homelessness and health care based on a unified message from voices in the field. After searching the published peer-reviewed research from the past few years, the committee interviewed academic and community-based researchers, healthcare providers, program administrators, and other professionals known for their commitment and contributions to homelessness research. This report summarizes the collective wisdom generated from this effort.

Current Research Priorities

Research on topics related to homelessness and health care is limited, and **interviewees criticized the current literature for leaning too heavily toward descriptive research, for overemphasizing issues of substance abuse and mental health, and for including only homeless persons already receiving services**. A proxy scan of the published literature completed for the years 2001-2004 confirmed these perceptions and critiques.

Future Research Directions

Asked to identify those research topics which should be of highest priority, interviewees largely agreed on **several key themes**, including:

- The research needs to shift from description to action - the emphasis should be on **translating research into practice**. Numerous interviewees talked about the need to assess interventions and models that work, such as the HCH model for providing health care, harm reduction, and housing initiatives.
- Some of the overarching questions remain unanswered, such as **how to prevent homelessness by addressing structural and societal causes.**
- More needs to be known and understood about some **subgroups** within the homeless population, including families with children, adolescents and young adults, and homeless persons living in rural areas.
- Health-specific research should **address the practical challenges** of helping homeless persons manage chronic diseases, and designing strategies to assist homeless persons in accessing the health care and treatment they need.
- Applied policy research is needed to better explain the issues related to homelessness more effectively to decision-makers, and to **engage policy-makers** who have a vested interest in housing and support services solutions.

Underlying many of the comments made about research priorities was a pressing desire for **advocating change for homeless persons, and for actively using research to inspire both programmatic and policy changes**.

Improving Research and Overcoming Barriers

Funding for homeless-specific research is rare; the primary sources for research on homelessness and health care are federal government agencies and a handful of private foundations. Respondents suggested funders and grant reviewers need to be better educated about both the realities of homelessness, and of conducting research with and about persons who are homeless,

and researchers need to find ways to match the funders' aims if they hope to access funds. One of the implications of categorical funding is the **rising control funding agencies have over defining research questions and directions**. Interviewees stressed the danger inherent in this transition, namely that it can lead to victim-blaming, and the systemic causes and solutions for homelessness can get lost. For example, some of the most fertile funding sources for researchers in this field are in the areas of substance abuse and mental health; while certainly these are prevalent issues for many homeless persons, a focus on these problems to the exclusion of the structural realities responsible for that prevalence and the barriers preventing their resolution is simply another way of blaming homeless persons for that situation.

Generally speaking, funding sources which can be tapped tend to require a level of scientific rigor not realistic for methodologies that work with this population and the environments where they live and receive services. For example, the scientific model of research generally assumes subjects who are easy to locate and enumerate, and are residentially stable. By design, homelessness research requires community-based participation, yet successful collaborations between academic researchers and community care providers can be complicated by the conflicting cultures of their work environments and goals. **There is a need to build and support a community of individuals interested in homelessness research, and in training them in the skills to carry it out**. Some of the strategies these interviewees recommended for improving research included: **embracing alternative methodologies - such as qualitative and community-based participatory research – and building credibility for them in the scientific community; developing and nurturing collaborations between academic researchers and service providers; and learning the concerns homeless people have in participating in research to find ways to involve them without being coercive, intrusive or exploitative.** Asked to identify some specific roles which the National HCH Council and HCH Clinicians' Network could play in improving research, they mentioned ways of facilitating the research process – such as bringing researchers with common interests together and nurturing researcher/provider collaborations, of building the capacity to do research by supporting researcher training, and of helping to increase the impact of existing research.

Next Steps

The findings presented in this report will provide the basis for developing a National Health Care for the Homeless Research Agenda, which will articulate short and long-term goals and research priorities in the area of homelessness and health care. This Agenda is a pioneering attempt to move research toward greater responsiveness to those individuals fighting to overcome homelessness, and toward the eradication of homelessness itself.

INTRODUCTION

Disparities in health and health care access for homeless persons are persistent and well documented. Peer-reviewed publications disseminate research findings in the broad fields of homelessness and health, yet not all effectively facilitate improvement of health care practice and policy. Research topics of great importance to health care providers working with this population remain unexamined; furthermore, studies that might reveal valuable information frequently do not include this population, making the significance of the findings difficult to interpret.

In early 2004, the Research Coordinating Committee of the National Health Care for the Homeless (HCH) Council and HCH Clinicians' Network launched an effort to assemble evidence on the status of these issues, with the goal of articulating future research directions with a unified voice from the field of homelessness and health care. After searching the published peer-reviewed research from the past few years, the committee began to gather the collective wisdom of academic and community-based researchers, formerly homeless persons, healthcare providers, program administrators, and other professionals known for their commitment and contributions to the field. This report summarizes the findings of this data gathering effort; these findings provide a base of knowledge about current research priorities, point to critical research needs and gaps, suggest priorities for future research directions, identify issues that pose barriers, and articulate potential strategies for addressing those priorities and overcoming gaps and barriers.

This project represents an important step toward the development of a National Health Care for the Homeless Research Agenda, a pioneering attempt to move research toward greater responsiveness to those individuals fighting to overcome homelessness, and toward the eradication of homelessness itself.

Information Sources

Proxy Literature Scan

A proxy literature scan was completed to provide a snapshot of the published literature on homelessness and health care over the past few years. The Research Coordinating Committee publishes a quarterly newsletter entitled the "HCH Research Update" which is a compilation of abstracts from articles published in the field of homelessness and health care. Several major databases are searched for these abstracts, and include journals not only in a wide range of medical journals, but also in associated fields, such as anthropology, religion, sociology, psychology, law, and social work. The NHCHC Research Specialist reviewed the Update newsletters from January 2001 through January 2004, first to develop a taxonomy for theme areas, and second to tally the number of articles published in those areas. Within each theme area, the specific subpopulation being researched was also recorded. Where overlap occurred within and between the categories observed in a single study, an attempt was made to select the primary focus. Only studies based in the United States were included in the scan.

Interviews

With assistance from the National HCH Council staff and governing members, and HCH Clinicians' Network Executive and Steering Committee members, the Research Coordinating Committee (RCC) compiled a list of researchers actively working in the field of health care and homelessness. A letter inviting researchers to participate in a 15-20 minute interview was drafted and sent in February 2004 (see Appendix B for a copy of the recruitment letters). RCC members followed up with the letter recipients to schedule and then complete those interviews. The same process was used to compile a list of relevant organizations and interview representatives from those organizations; the recruitment letter to those representatives was sent December 2004. Nearly all of the researchers and representatives invited to complete an interview participated. Several additional respondents were identified during the interviews, and were subsequently contacted for their input. In total, 45 individuals completed interviews. (See Appendix A for a list of these interviewees).

The following questions were used by the interviewers to guide the open-ended interviews:

<u>Researchers</u>

- Which research issues or topics do you consider of highest priority? Why?
- Are there research topics under investigation that should be studied differently? If yes, how might these studies be improved?
- What research topics seem to be drawing the most attention?
- What are barriers that you have experienced in conducting research in this field? What are ways to overcome these barriers?
- What are sources of financial support for homelessness research?

<u>Organizational Representatives</u>

- Which issues around homelessness or housing and health do you think need further investigation?
- What research issues or topics seem to be commanding the most attention?
- What are impediments that organizations such as yours face in funding or supporting research on underserved populations? Do you have thoughts on how these might be overcome?
- What are sources of financial support for research on homelessness and health? If you are with a funding agency, do you have priorities for funding research that we should know about?
- Is there anything in your organization's strategic plan that might be helpful for us to consider as we plan our own organization's future?

<u>All Informants</u>

- Are there other issues or concerns that you would like to bring to the attention of the Research Coordinating Committee as it develops this National Research Agenda?

Group Discussions

Relevant committees of the HCH Council and Network were invited to provide input into this process during one of their regularly scheduled meetings. These group discussions were held with the Council governing members, HCH Clinicians' Network Executive Committee and Steering Committees, Policy Committee, and the Pediatrics Work Group. In addition, the Research Coordinating Committee members invited all of those researchers who had been interviewed for the research agenda, as well as other interested parties, to participate in a research roundtable discussion at the annual Health Care for the Homeless Conference in June 2004 to share their own research experiences and contemplate future research priorities (Roundtable discussion participants are listed in Appendix A).

CURRENT RESEARCH PRIORITIES

Perceptions of Interviewees

All of the interviewees were asked to comment on which research topics they perceived as drawing the most attention. Although they could respond with a variety of audiences in mind - funders, the public, their colleagues – most answered in unison: very few topics related to homelessness are drawing any attention at all.

> *"Nobody's interested in homelessness."*
>
> *"Homelessness is an issue that went away."*

The other topics mentioned in response to this specific question, each mentioned by approximately four interviewers, included: chronic homelessness and the disabled, housing (including supportive housing and the Housing First initiative), and substance abuse/mental health issues.

As will be noted in subsequent sections of this report, interviewees criticized current homeless healthcare literature for leaning too heavily toward descriptive research; for overemphasizing issues of substance abuse and mental health; and for failing to assess representative samples of homeless persons – that is, basing study findings on only those receiving services in a clinic or shelter setting.

Literature Scan Findings

The scan appears to support the perception that homeless healthcare literature is limited. (Findings from the proxy literature scan are summarized in a table on the following page.) On average, fewer than eighty articles were published each year in peer-reviewed journals on research studies which included homeless persons as subjects, and/or were deemed directly relevant to the work done in the homelessness and health care field. This number seems especially low given the large number and types of journals searched to find these studies. In addition, the diversity of health issues assessed is quite small: nearly all of the articles on health status or healthcare needs are general descriptive studies, and a majority of the disease-specific articles focused on HIV/AIDS or TB.

Other perceptions noted by interviewees are also confirmed by this scan. For example, most of these published articles are based on descriptive research, and nearly all were conducted with shelter-based or hospital-based samples of homeless persons. Service utilization and access studies, combined with those focused on service innovation made up nearly two-fifths of those included in the scan. Although it appears that substance abuse and mental health may not be overemphasized (together comprising just 15% of the articles), it should be noted that many of the articles listed in other categories relate directly to these issues but were not deemed the primary focus of the study. And, individuals characterized by substance abuse and/or mental illness are the main subjects of one-quarter of all of the studies, and a majority of studies assessing service innovations.

In addition to the subpopulations listed in the table, a handful (in some cases just one or two) articles were written on the following specific subpopulations: Gay/Lesbian/Bisexual/ Transsexual (youth-only), male, rural, elderly, African American, undocumented, and incarcerated.

HCH RESEARCH UPDATE ARTICLES: 1/01-1/04							
		SUBJECT SUBPOPULATION					
THEME AREA	***Subtotals***	**Adults (general)**	**Children/ Adolescents**	**Women/ Families**	**Veterans**	**Mentally Ill**	**Substance Users**
SERVICE UTILIZATION AND ACCESS *Focus is on service use patterns, increasing access to services*	**48** (21%)	**12**	**5**	**8**	**6**	**9**	**8**
General	*38*	9	5	7	4	6	7
Cost studies	*3*				1	2	
Entitlements	*4*	1		1	1	1	
Managed care impacts	*3*	2					1
DISEASE-SPECIFIC *Focus is on specific disease: risk factors, prevalence, treatment*	**47** (21%)	**26**	**8**	**6**	**2**	**1**	**4**
Tuberculosis	*11*	11					
HIV/AIDS	*20*	8	6	5			1
Hepatitis	*8*	2			2	1	3
STDs	*3*		2	1			
Misc. (Includes 1 each: Cardiovascular; Ratborne Pathogens; Soft Tissue infections; Methicallin–Resistant Staphylococcus Aureus; Cancer)	*5*	5					
SERVICE INNOVATIONS *Focus is on development of and/or evaluation of services for homeless persons*	**41** (18%)	**8**	**6**	**4**	**1**	**20**	**2**
General	*32*	3	6	4	1	16	2
Ethics in service	*2*	1				1	
Education/Training	*4*	2				2	
Case Management	*3*	2				1	
HOMELESSNESS AND HOUSING *Descriptive papers on homelessness and/or housing*	**24** (10%)	**9**	**6**	**3**	**1**	**4**	**1**
General	*10*	4	3	2			1
Risk Factors for homelessness	*10*	2	3	1	1	3	
Effects of housing on health	*4*	3				1	
HEALTH STATUS *Focus is on health status and/or healthcare needs*	**19** (8%)	**2**	**9**	**5**	**1**	**2**	**0**
General	*17*	2	9	5		1	
Oral Health	*2*				1	1	
MENTAL HEALTH *Focus is on mental health problems, behaviors, treatments*	**19** (8%)	**6**	**3**	**9**	**0**	**1**	**0**
General	*14*	5	2	7			
Social support	*3*		1	2			
Spiritual health	*2*	1				1	
SUBSTANCE ABUSE *Focus is on substance using behaviors, prevalence, treatments*	**15** (7%)	**9**	**4**	**1**	**1**	**0**	**0**
RESEARCH & EVALUATION ISSUES *Focus is on the process of conducting research or evaluations with (or about) homeless persons, assessment tools*	**15** (7%)	**5**	**3**	**1**		**4**	**2**
General	*12*	3	3			4	2
Ethics	*3*	2		1			
TOTALS	**228**	**77** (34%)	**44** (19%)	**37** (16%)	**12** (5%)	**41** (18%)	**17** (7%)

FUTURE DIRECTIONS FOR RESEARCH

Translate Research Into Practice

Many respondents said the research in this field needs to shift from describing homeless populations, their various health issues and needs, and innovations in interventions, toward narrowing the gap between - or "translating" - research into practice. More than one-third specifically mentioned a need to assess interventions to know what works and for whom among the homeless population; phrases such as "models that work", "best-practices" and "evidence-based practice" recurred throughout these discussions.

> *"We're getting past the descriptive stage and [to] interventions and whether they work or not."*
>
> *"Most models – even HCH – aren't evaluated. ...for any kind of intervention – transitional, supportive housing – do they work? "*
>
> *"I would prioritize anything that has to do with models that work, that have practical significance."*
>
> *"We know enough about the population now, so that is not appropriate anymore. We need to look at action."*
>
> *"We do efficacy studies, but the problem is how those get translated to the outside world."*

Within this category, interviewees gave specific examples of interventions or practices they believed worthy of further investigation. Three of the most common examples included the recovery process, systems integration, discharge planning, and housing.

- The Recovery Process – Several respondents indicated a need to understand the recovery process better, and to test what does and does not work (and for whom) those practices increasingly utilized and valued in the field like harm reduction techniques and motivational interviewing.

  > "*motivational interviewing seems to work, but when applied to the homeless population, there aren't studies of how effective it is or in what configuration."*
  >
  > *"people are reluctant to look at [harm reduction], yet more and more evidence indicates you need to start with the addiction to move to recovery."*

- Systems Integration – While in practice it is generally understood that breakthroughs for this population are most apt to occur in a system which integrates all types of care (e.g. primary care, substance abuse, mental health, social support), this is a model of care which is largely unexplored. (e.g. the HCH model)

- Discharge Planning – Several interviewees commented on a need to understand institutional discharge planning processes better. ("*you hear about the importance of discharge planning in preventing homelessness…what people don't talk about is a best practice.")*

- Housing – This includes the value of Housing First approaches and other community-based efforts to decrease homelessness through housing programs and interventions.

A few mentions were made of the fact that even when best practices studies are conducted, they seldom are focused on programs and agencies which are not well funded. One example of this is the Health Care for the Homeless model for providing healthcare, and for innovative interventions produced within that model. A few also discussed the need to accompany intervention studies with cost-benefit analyses.

Structural Causes of Homelessness

Respondents also expressed the need to understand how to prevent homelessness, or, conversely, to better understand the causes of homelessness, as a top priority. They said some of the most important questions about homelessness, such as why it continues to exist, remain unanswered.

> *"We need to understand the causes of homelessness. Why should a wealthy nation have this problem?"*
>
> *"Why is there no national health care system? Why is there no affordable housing?"*
>
> *"Is homelessness a cause or consequence of other conditions?"*
>
> *"I would love to see research on the social and structural factors contributing to homelessness. Current research focuses on individuals and ignores the question about societal and structural factors."*
>
> *"[We need to get] a handle on the issue of chronic homelessness and chronicity, to understand …the revolving door of homelessness, and what are the contributing factors."*

Embedded within these broad questions are building-block questions which need to be answered along the way. Many of these echo the practices and interventions mentioned as high priorities in the previous section. For example:

- We need to know which methods work for engaging homeless people to obtain services and to move into housing. (*"The number one issue is a …general one: How do we move people out of homelessness, into housing, and help them stay there?"*)

- Prevention questions related to institutional discharge, such as the responsibilities of those major public institutions which discharge people but do not have responsibilities for housing (e.g. mental health, corrections, emergency services). A systemic perspective should be used to examine discharge planning, and determine how it relates to people becoming homeless.

- Role of health and social services in preventing and ending homelessness. For example, what are the health risks or costs to hospitals and child welfare departments for those who drop out of substance abuse treatment or are never able to access treatment in the first place? And, what are the effects of health and mental health on becoming and remaining homeless?

- The effects of systems level policy on homelessness needs to be examined. For example, how do changes in health policies – like Medicaid reimbursement and a lack of health insurance - directly impact homelessness?

- A handful of interviewees suggested a greater emphasis on cross-cultural or international homelessness to learn from other developed countries about the causes of homelessness.

Subpopulations

Many of those interviewed believed more needs to be known and understood about some subgroups within the homeless population, in part to enable research findings to be more quickly and effectively translated into practice. Subgroups mentioned most frequently as those often overlooked, in spite of increasing numbers within those groups, include families, adolescents and young adults, and rural populations.

> *"We call it a population, when really it's a lot of populations. …When research gets more specialized, it will help bridge the gap between researchers and practitioners. [Right now] we give them research which is much too broad."*

Families and children Several interviewees noted that the current Chronic Homelessness Initiative excludes families with children in its definition of "chronic homeless" persons, even though families comprise the fastest growing group of persons becoming homeless. Others expressed a need to know more about the long-term effects of homelessness on parents and children, raising issues such as the mental health needs of young homeless children, and the impact of youth trauma on homelessness.

Adolescents and Young Adults Adolescents or young adults are another fast-growing homeless population about which little is understood, particularly those "aging out" of the foster care system. Specific topics noted include: the types of services which best serve their needs; service utilization patterns and health status of adolescents; and general information about youth living on the street. *("No one really knows which types of services are good for youth – most are holdovers from adults.")*

Rural The vast majority of research conducted on homeless populations occurs in urban settings, mostly due to access and other practical reasons. Nevertheless, this focus has left a limited knowledge base about persons who are homeless in rural areas, as well as what services and models work for them.

Health Care and Access

The interviewees who named disease-specific research topics as the highest priority – primarily clinicians - focused their comments on the management of chronic disease. For example, *"In my work with people with severe and persistent mental health problems, I see a lot of chronic health disease problems, such as diabetes, high blood pressure, other coronary diseases, etc. that often fall beneath the radar of providers. What are effective ways to treat these issues while homeless, and then provide continuity after they've left shelters and are living in housing?*

Others discussed more generally the practical challenges of helping their homeless patients access care; for example, caring for patients when necessary treatment and services are unavailable; helping them transition out of HCH clinics when ready; working with shelter staff; coping with high staff turnover, and so on. One researcher suggested research is placing too much emphasis on disease and should take a more holistic approach: "*The current research is so disease-based that it misses consideration of spiritual and mental health needs.*"

Affect Policy

Underlying most of the comments made about research priorities was a pressing desire for advocating change for homeless persons, for actively using research to inspire both programmatic and policy changes. This desire can be seen in the calls already discussed: to assess interventions and translate them into practice, to prevent homelessness by addressing structural and societal causes, to learn more about previously overlooked subpopulations to bridge the gap between research and practice sooner, and to make the health encounter more appropriate and effective. Many respondents even more directly stated a need for research which affects policy and goads politicians to make systemic changes. For example, interviewees urged the need for applied policy research, to better explain the issues related to homelessness more effectively to politicians and those in decision-making capacity, and to engage policy-makers with a vested interest in housing and support services solutions.

> *"We've done our studies based on our own needs rather than going to policy makers and asking them what they need to know. We need to produce research that's more usable by policy-makers."*

> *"We don't have to wait for the answers to the long-term questions, such as why do people become homeless, to do a lot of effective things now."*

IMPROVING RESEARCH AND OVERCOMING BARRIERS

Funding Sources and Strategies

A large majority of the interviewees asserted there is limited funding for homeless-specific research and/or that the existing funding is too categorical and restrictive.

> *"There really aren't any (funding sources), specifically..."*
>
> *"Since ...the early to mid-80s, there has been very little research funded on homelessness."*

Funding Sources

Probed to identify existing funding sources for homeless health care research, most mentioned at least one of the following federal sources:

- U.S. Department of Health and Human Resources, and associated departments within the National Institutes of Health (especially the National Institute of Mental Health, the National Institute on Alcohol Abuse and Alcoholism, and the National Institute on Drug Abuse); the Agency for Healthcare Research and Quality; and the Substance Abuse and Mental Health Services Administration (especially the Center for Mental Health Services);
- U.S. Department of Housing and Urban Development; and,
- Department of Veteran's Affairs.

Some also mentioned private foundations as potential funding sources for research, though only a few mentioned specific foundations (Gates Foundation; Hoggs Foundation; Kellogg Foundation; McArthur Foundation; Robert Wood Johnson; Melville Trust; and Soris Foundation). While private foundations were generally considered desirable sources of funding due to their political neutrality (*"... private foundations have fewer strings attached and are less politically motivated."*), they were also considered to be quite scarce, and more interested in funding services than research.

One implication of funding sources becoming categorical (e.g. disease-specific) is that the funding organizations assume greater control over the research questions that can be asked. (See further discussion of this dilemma under "Framing the Research Question" below)

> *"The way research has been funded by the Federal government, it flows with the whims of the government and what is 'hot.' [Researchers end up] chasing dollars, so the available funding is what drives what is studied, rather than the other way around."*
>
> *"The Federal government is the primary source, although there is not as much freedom to focus in and do research on homelessness as there used to be. In the past, it was more investigator initiated, now it is more specific and categorical."*

And, many of those who had pursued federal funding sources for their research expressed frustration with perceived lack of understanding about homelessness among funders and grant reviewers. *("Funders have misconceptions about the nature of the problem." "...reviewers don't appreciate the other dimensions associated with homelessness.")*

Strategies with Funders

Asked how to overcome barriers in attempting to access scarce research funding, two primary strategies emerged: educate funders and grant reviewers, and find ways to tie the aims of homelessness research more closely to funders' aims.

Educate Funders and Reviewers

Many interviewees suggested funding agencies and those reviewing research grant applications need to be better educated about both the realities of homelessness, and of conducting research with and about homeless persons. This is not to say funders are not receptive to research that can improve homeless healthcare, but that placing homelessness research in direct competition with research more conducive to scientifically rigorous methodologies can place the former at a profound disadvantage. (See detailed discussed of some of these issues below) One organizational representative suggested that while education is key, it can be delivered most effectively by involving the funder because h/she hears directly about the need from the provider.

Matching the Funders' Aims

Numerous interviewees suggested one way to respond to the lack of interest in homelessness per se was to contextualize homelessness within the goals of the funding agency, to begin with the agency's aims and find a way to fit homeless issues into those.

> *"It was only when I figured out how to study homelessness in the context of substance abuse that I could tap into an established funding stream. How we frame the questions is most important part of this."*
>
> *[Re. a successful bid for a federal grant]: "Homelessness was not the drawing card. You have to find some hook other than homelessness itself. To look at homelessness per se there's no funding sources."*
>
> *(From a funder:) "We tend not to focus on narrow populations...you need to consider homeless a subset of the uninsured."*
>
> *"I don't think I've ever seen an RFP [request for research proposal] for homelessness, know what I'm saying? As advocates in our field we need to make our issues relevant to the homeless population."*

Several interviewees noted a need to broaden the definition of homelessness beyond a literal usage, and to conceptualize health beyond the biomedical realm. The following statements speak to the latter:

> *"We have to...tie our outcomes to criminal justice, health service utilization and medical costs, employment..."*

"We need to broaden the net. If we're going to talk about interventions to reduce prevalence of TB or noncompliant treatment for TB, we should also look at consequences of incarceration rates, employment, entitlement provisions, etc. ...I say that more specifically to our clinical researchers, who heed to reach out to involve social scientists and criminologists. Do a better job of contextualizing."

Framing the Research Question

As noted earlier, many of those interviewed are motivated to study and think about issues related to homelessness and health care in part by a desire to advocate for systemic societal change; those motivations at times can clash with those of political motivations of federal government agencies or private foundations providing funding for research. For example, some of the major funders (e.g. NIMH, NIAAA) are concerned about the specific problems addressed by their agencies, which means the research question must assume that problems exist within the study subjects (e.g. homeless persons). This both reverses the research process and further stigmatizes the subjects as being defined by those problems. Framing research questions consistent with and meaningful for these potentially conflictual aims can therefore be a very delicate enterprise. This section summarizes some of the concerns and strategies raised during discussions with individuals striving to achieve this difficult balance.

Institutionalizing Homelessness

As mentioned above, one of the implications of increasingly specialized research is the rising control funding agencies have over defining research questions and directions. Interviewees stressed the danger inherent in this transition, namely that an overemphasis on individuals and individualized experiences can lead to victim-blaming, that the systemic causes of homelessness can get lost. The following comments are typical:

"In framing the questions, we shouldn't create a simplistic or political process that creates a mentality of simple evil culprit and homeless as victims of issues beyond their control – nor is it appropriate to frame it as homeless-by-choice. Both perspectives distort the picture."

"if research becomes so shortsighted that the goal is to make homeless people healthier but not how to eradicate homelessness we run the risk of institutionalizing homelessness."

"the more institutionalized the problem becomes, the more money that goes into naming things, creating infrastructures around homelessness. I worry to what extent that just ingrains the problem further."

Overemphasis on Mental Health and Substance Use

Several explicitly expressed concern about the potential for an overemphasis on the problems of mental health and substance abuse, in part because agencies representing these issues tend to be fertile sources of funding. This is not to say these problems are not prevalent among the homeless population or that they should not be studied, but rather that a focus on these problems to the exclusion of the structural realities responsible for that prevalence and the barriers preventing their resolution is simply another way of blaming homeless persons for their situation. (*We should be looking at society as much as individual homeless folks. Let's look at what's wrong with society;"* and, "*We need to think more globally, look at the larger environmental questions that encourage and discourage substance abuse.")*

Avoid Overgeneralizations

Several interviewees voiced the danger of generalizing too broadly about the homeless population. They commented, for example, on the fact that many issues are local and those local factors need to be differentiated even within the same city or region. Cultural and ethnic differences also should not be overlooked and subsumed in generalizations about "the homeless." While there is a need to focus on the systemic and structural causes of homelessness and to maintain a national focus, as noted earlier, the diversity within the population should not be ignored.

Methodological Issues

Methodological barriers prevent rigorous, scientific research with the homeless population and lead to an overemphasis on non-experimental studies. The most commonly mentioned methodological issues were the difficulty of obtaining a representative sample, using randomization, and enumerating the population.

> *"Doing research in the real world is essential but very difficult."*

Rigorous scientific research is based on a model of clinical trials, wherein a representative sample of the study population is randomized into a test group and a comparison group. This model is based on a number of assumptions not relevant to research involving homeless persons, including that the population can be enumerated, and that subjects are easy to locate and residentially stable. Given that some homeless persons may not want to be located, are frequently mobile, and either may not access any services at all or at least not the same services consistently, increases the complexity and cost of attempting a representative sample to a point that most stop trying. One researcher who was determined to go beyond the shelter system to obtain a sample of homeless families ended up with most of her subjects from the shelters *"the more you try the more you realize you're failing."* And, obtaining a random sample is of course also nearly impossible given that most communities are unable to obtain a reliable count of homeless persons. Despite this "frisky denominator" issue, a great deal of emphasis is given to the epidemiology of homelessness. This is clearly frustrating for those who understand the complexity and expense behind trying to obtain a reliable count: *"The idea that we need to know how big the population is before we can do anything is a fallacy and an excuse for not doing anything."*

Scientifically validated instruments are also often inadequate for homelessness studies, both because they are not culturally competent (e.g. SF36 includes golf to describe activity), and because they are not able to measure incremental changes (e.g. substance abuse measures often look at abstinence versus not abstinent, and do not look at reduction of harm or risk).

Given these and other barriers, the vast majority of research conducted is non-experimental and based on convenience samples. While certainly this research is valuable, the picture it creates is limited and biased. One researcher gave an example which illustrates some of the unintended consequences of conducting research in this manner. A federal health agency conducted a HIV sero-prevalence study (in the 1980s) by using blood drawn from individuals who had received services in a migrant farmworker clinic. (They could thus keep the study anonymous and not have to get informed consent.) Yet only the very sickest workers went to this clinic - the healthiest were working - so the sample was inherently biased. Nevertheless, the researchers conducted the study and found a very high prevalence among their biased sample, yet reported the findings as though they were representative of the migrant farmworker population. In short, this kind of study can be very misleading and further stigmatize vulnerable populations.

Even cross-sectional research which is done respectfully and presented with care, however, cannot provide the same depth or breadth of information a longitudinal study would. To truly understand the effects of interventions, to know the factors precipitating homelessness, or to understand the long-term impacts of homelessness on youth, longitudinal studies are needed.

Alternative Methodologies/Approaches

Many of the interviewees recommended that researchers in this field give more attention to alternative methodological approaches - especially qualitative/ethnographic methods and community-based participatory research – rather than trying to fit their research into a model that is unworkable. Nonetheless, these approaches have many advantages when addressing issues related to homelessness and homeless healthcare. For example, qualitative/ethnographic methods (particularly as part of a mixed-method study) are able to capture greater complexity, and community-based participatory research enables a greater level of involvement and input from homeless persons and providers, thus enriching the findings and increasing the capacity to do research.

> *"We know the population is heterogeneous, and qualitative research can be a lot more instructive."*
>
> *"Research should be more strengths-based, to understand survival skills and resilience strategies."*
>
> *"Community-based participatory research model is ideal."*
>
> *"...need to use mixed methods because you get contextual information as well as complexity. ...we distance ourselves with the problem...stories help connect and make it real."*

Community-Based Research Issues

Researchers intent on conducting research in community-based settings where homeless persons reside and/or receive services face an additional layer of complexity, largely brought on by conflicting "cultures" of academic researchers and care providers.

> *"The biggest barrier is the different culture between direct care providers and researchers. As a provider, there is an insistence on services first."*

> *"treatment programs are set up to provide the services any way you can and as quickly as you can – research is about getting it done in a specific way, and if that means it goes slower that's the way it is."*

Some of the issues interviewers raised as resulting from this type of research include:

- Inconsistent and fragmented record-keeping (within and across agencies)
- Mismatch between data needs of researchers, and data collected by service agencies
- Service providers are overextended meeting multiple funders' data requirements so they can't collect more (e.g. outcomes data rare rarely among funder requirements, so these get left out)
- Staff, space, and administrative resources to carry out research can be scarce
- Follow-up of subjects can be extremely time-consuming and costly
- Staff and provider turnover can cause delays
- Though the input of homeless persons into the entire study, beginning with the research design, is critical, it is often difficult to find funding for this.

Many of those interviewed urged more and better collaborations between providers and researchers. Some had successfully navigated community-based research with valuable results; following are some of the "lessons learned" from those successes.

- Form an alliance with a research center (or university) that is willing to work with a treatment provider – it takes tremendous resources, but this is a workable model
- It takes time and trust to develop community partnerships
- Real partnerships share the power *and* the money

Another important part of enhancing the ability to carry out community-based participatory research is increasing the number of researchers interested in studying in this field, and in developing their skills to carry out research within it.

> *"We do need to view [this] as an infant field that needs to be grown and more rigorous to become more legitimate."*

> *"Homelessness research by design requires community-based or community engagement..... which requires a whole set of research skills that the research community tends not to acknowledge. ...Academia follows a mentorship model. Mentorship for people interested in doing this research is incredibly important if we're going to have a critical mass of homeless (sic) researchers. To make the advances needed we need more people to do this."*

This is not a simple task, particularly because of a common bias among funders (and to some extent researchers) against participatory methods in community settings, or even just involving community organizations in doing research. Hence, there is, as one researcher put it, "a lack of prestige and commitment from the scientific community" for research on homelessness. A few of the academic researchers interviewed commented on how little support they receive for their work on homelessness either from colleagues or from the academic environment generally. As one physician-researcher remarked, *"I had a well-respected mentor a couple of years ago say you're committing academic suicide by doing homelessness research."*

Consumer Involvement

Several respondents also commented on the need to find ways to involve homeless persons in ongoing studies; a great deal of research systematically excludes homeless persons by making residential stability a requirement for inclusion. Yet, homeless persons comprise a vulnerable population, and many interviewees noted the importance of acknowledging those vulnerabilities and addressing them in an ethical manner. The most often-cited examples of this emerged from the process of obtaining consent, particularly from adolescents or individuals with cognitive impairments, without being exploitative, coercive, or intrusive. A few researchers noted that very little is known about what homeless people think about participating in research, though knowledge of their concerns and attitudes would enable researchers to be more responsive.

Role of the National HCH Council and HCH Clinicians' Network

Interviewees had varying levels of knowledge about or experience with the National HCH Council and HCH Clinicians' Network, so not all were able to contemplate appropriate roles for the organization. Those familiar with the mission and work of the Council and Network, however, recommended a stronger role in research would be both appropriate and desirable. Their specific suggestions generally fell into one of three areas: facilitating ongoing research; building the capacity for doing research in the field; and increasing the impact of existing research.

Facilitating Ongoing Research

- Bring researchers with common interest in homelessness and health care together:

  "Putting together researchers with overlapping interests…"

  "We don't have the interdisciplinary infrastructure to connect the different people doing research on homelessness. We have centers on cancer, etc., but none on homelessness – could bring different disciplines together in a concerted way: anthropologists, primary care and mental health clinicians, housing, epidemiologists, etc."

  "The biggest issue is to go from more piecemeal research to more integrated projects. I would like to participate in a collective multi-city project."

- Encourage and nurture provider/researcher collaborations; interest researchers in clinical information that matters to homeless persons.

- Help researchers obtain representative samples for their studies – for example, encourage providers who work with hard-to-reach populations to work with researchers in accessing homeless persons who are not receiving services.

- Gain an understanding of homeless persons' attitudes and concerns about participating in research. Find ways to appropriately involve homeless individuals in the research process, particularly in the design phase.

Building Capacity

- Support training for researchers who are committed to serving these population. For example, implement a post-doc fellowship or a training program specifically for researchers who study homelessness and health. (One interviewee noted that the Kellogg Foundation is trying to put more focus on safety-net providers, and to train a cadre of researchers to study public health research.)

Publishing and Disseminating Research

- Encourage researchers "with a heart for our population" to present their work at the annual HCH Conference.

- Identify areas where substantial research has been done, and carry out a synthesis or meta-analysis of what is known and disseminate it; AHRQ publishes evidence-based reports on various topics, and could serve as a starting place.

- Increase the impact of the research that is being done, especially among policy-makers. *("The research we have isn't being paid attention to...")*

Next Steps

The findings from this accumulation of knowledge will provide the basis for developing a National Health Care for the Homeless Research Agenda, which will articulate short and long-term goals and research priorities in the area of homelessness and health care.

APPENDICES

A: List of Interviewees

(Note: an * beside the person's name indicates they were interviewed in their role as an organizational representative.)

Linda Anooshian, PhD
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Newton Centre, MA

*Anne Beal, MD, MPH
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Quality of Care for the Underserved
Commonwealth Fund

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Saint Vincents Catholic Medical Centers
Saint Vincents Manhattan
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Martha Burt, PhD
Center on Labor, Human Services and Population
Urban Institute
Washington, DC

Michael R. Cousineau, PhD
Associate Professor of Clinical Public Administration
School of Public Administration
University of Southern California
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Larry Crum, PhD
Research Triangle Institute
Research Triangle Park, NC

Dennis Culhane, PhD
Associate Professor
University of Pennsylvania
Philadelphia, PA

Ellen Dailey
Co-Chair, National Consumer Advisory Board
Boston, MA

*Debbie Dennis, MA
Vice President for Technical Assistance
Policy Research Associates, Inc.
Delmar, NY

*Kaytura Felix-Aaron, MD
Chief, Special Populations Research Branch
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Administration
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*Donna Haig Friedman, Ph.D
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John W. McCormack Graduate School of Policy Studies
University of Massachusetts Boston

John G. Gardin II, PhD
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The LifeLink
Santa Fe, NM

Lillian Gelberg, MD, MSPH
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Dept of Family Medicine
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Research Triangle Park, NC

*Carl Helvie, RN, DrPH
Past President
Caucus on Homelessness
American Public Health Association
Hampton, VA

Kim Hopper, PhD
Research Scientist
Nathan S. Kline Institute for Psychiatric Research
Orangeburg, NY

*Stephen Hwang, MD
Inner City Health Research Unit
St. Michael's Hospital
Toronto, Ontario

Catherine Karr, MD
University of Washington
Children's Hospital and Regional Medical
Seattle, WA

Russell Kellogg, MD
Saint Vincent's Hospital
Department of Community Medicine
New York, NY

*Stefan Kertesz, MD, MSc (*Note: Dr. Kertesz facilitated research roundtable discussion)*
Assistant Professor
University of Alabama at Birmingham
Divisions of Preventive and General Internal Medicine
Birmingham AL

Paul Koegel, PhD
Associate Director
The RAND Corporation
Santa Monica, CA

Celia Larson, PhD
Director, Health Care Evaluation
Metropolitan Health Department
Nashville, TN

Gary Morse, PhD
Community Alternatives: Innovations in Behavioral Care
St. Louis, MO

Adeline Nyamathi, RN, PhD
UCLA School of Nursing
Los Angeles, CA

James J. O'Connell, MD
Boston Health Care for the Homeless Program
Boston, MA

Thomas O'Toole, MD
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Michael Polgar, PhD
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Penn State Hazleton
Hazleton, PA

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*Larry Rickards, PhD
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*Amy Rynell
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Heartland Alliance
Chicago, IL

Sarena Seifer , MD
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Community Campus Partnerships for Health
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Paul A. Toro
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Beth Weitzman, PhD
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Robert F. Wagner Graduate School of Public Health
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*Carol Wilkins, MA
Director of Intergovernmental Policy
Corporation for Supportive Housing
Oakland, CA

*Barry D. Zevin, MD
Medical Director
Tom Waddell Health Center
San Francisco Dept. of Public Health
San Francisco, CA

Research Roundtable Participants
(Those listed above)
Stefan Kertesz (facilitator)
Stephen Hwang
Barry Zevin
Debra Dennis
Donna Haig-Friedman

(Participants not listed above)
Bechara Choucair, MD
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Rockford, Illinois

Shawn K. Bowen, MD
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Children's hospital at Montefiore
New York Children's Health Project
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Susan Montauk, MD
HCH Physician
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Marion Scott, MSN, RN
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Houston, Texas

(RCC Members, Listed in Acknowledgements)
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Susan Kline
Adi Gundlapalli
Jill Roncarati
Suzanne Zerger

B: Recruitment Letters

Letter to Researchers

Dear Colleague:

With support from the Health Resources and Services Administration, the National Health Care for the Homeless Council and HCH Clinicians' Network Research Coordinating Committee is developing a **National Health Care for the Homeless Research Agenda**. As a first step, we are gathering information from individuals such as yourself who are experienced in conducting research related to homelessness and health care.

As you know, disparities in health and health care access for homeless persons are well documented and persistent. Peer-reviewed publications publish research findings in the broad fields of homelessness and health, yet not all effectively facilitate improvement of health care practice and policy. Research topics of great importance to health care providers working with this population remain unexamined. Studies that might reveal valuable information frequently do not include this population, making the significance of the findings difficult to interpret. As providers and administrators, the Research Coordinating Committee wants to be proactive and address these and other problems systematically by documenting critical research needs and gaps and identifying feasibility issues that pose barriers.

Within the next two weeks, a committee member will contact you via e-mail and/or telephone to schedule a brief interview, which we anticipate will take 15 – 20 minutes. Specifically, we want to hear your thoughts in response to questions such as the following:

- Which research issues or topics do you consider of highest priority? Why?
- Are there research topics under investigation that should be studied differently? If yes, how might these studies be improved?
- What research topics seem to be drawing the most attention?
- What are barriers that you have experienced in conducting research in this field? What are ways to overcome these barriers?
- What are sources of financial support for homelessness research?
- Are there other issues or concerns that you would like to bring to the attention of the Research Coordinating Committee as it develops this National Research Agenda?

We believe that developing this National Research Agenda is a vital step in addressing persistent disparities in health and health care access for homeless individuals. We welcome your participation and thank you in advance for your thoughtful consideration of these issues.

Sincerely,

Dr. Aaron Strehlow
Chair
Research Coordinating Committee

John Lozier, MSSW
Executive Director
National Health Care for
the Homeless Council, Inc.

Brenda Proffitt, MHA
Director
HCH Clinicians' Network

Letter to Organizational Representatives

December 2004

Dear Colleague:

With support from the Health Resources and Services Administration, the National Health Care for the Homeless Council and HCH Clinicians' Network Research Coordinating Committee is developing a **National Health Care for the Homeless Research Agenda**. As a first step, we gathered information from individuals across the country experienced in conducting research related to homelessness and health care. Now, we want to hear from organizational representatives such as you for further guidance.

As you know, disparities in health and health care access for homeless persons are well documented and persistent. Peer-reviewed publications disseminate research findings in the broad fields of homelessness and health, yet not all effectively facilitate improvement of health care practice and policy. Research topics of great importance to health care providers working with this population remain unexamined. Studies that might reveal valuable information frequently do not include this population, making the significance of the findings difficult to interpret. As providers and administrators, the Research Coordinating Committee wants to be proactive and address these and other problems systematically by documenting critical research needs and gaps, and identifying feasibility issues that pose barriers.

Within the next two weeks, a Research Coordinating Committee member will contact you via e-mail and/or telephone to schedule a brief interview, which we anticipate will take 15 – 20 minutes. Specifically, we want to hear your thoughts in response to questions such as the following:

- Which issues around homelessness or housing and health do you think need further investigation?
- What research issues or topics seem to be commanding the most attention?
- What are impediments that organizations such as yours face in funding or supporting research on underserved populations? Do you have thoughts on how these might be overcome?
- What are sources of financial support for research on homelessness and health? If you are with a funding agency, do you have priorities for funding research that we should know about?
- Is there anything in your organization's strategic plan that might be helpful for us to consider as we plan our own organization's future?
- Are there other issues or concerns that you would like to bring to the attention of the Research Coordinating Committee as it develops this National Research Agenda?

We believe that developing this National Research Agenda is a vital step in addressing persistent disparities in health and health care access for homeless individuals. We welcome your participation and thank you in advance for your thoughtful consideration of these issues.

Sincerely,

John Lozier, MSSW
Executive Director
National Health Care for
the Homeless Council, Inc.

Brenda Proffitt, MHA
Director
Health Care for the Homeless
Clinicians' Network