

# **Collecting Better Data in Supportive Housing: Industry Problems and Potential Solutions**

By

Robert Newcomer, PhD

Center for Personal Assistance Services  
University of California  
3333 California Street, Suite 455  
San Francisco, CA 94118  
(415) 476-1408 email [rjn@itsa.ucsf.edu](mailto:rjn@itsa.ucsf.edu)

## Abstract

Record systems covering licensed and unlicensed supportive housing facility characteristics and staffing; as well as resident characteristics and resident outcomes are not universally compiled. The absence of such information impairs planning, innovation evaluation, quality assurance, and consumer choice. This paper discusses information potentially obtainable from selected existing administrative data (e.g., licensing applications, hospital discharge abstracts, claims) and national population surveys (e.g., National Health Interview Survey, American Housing Survey). With some modifications these data sources could better capture information about the population living in licensed and unlicensed supportive housing and the quality of care provided.

Key words: aged, data systems, service indicators, evaluation, assisted living, residential care

Most of the data collected and available about long term care in the US is oriented to either persons living in the community or those in nursing homes. Other segments of the long term care system (e.g., assisted living, board & care, residential care) are much less well understood, and without population surveys or administrative data systems that facilitate community, state, or national level monitoring of resident populations or service supply. The attention given and data available for nursing homes is justified historically by the number of persons served and the high expenditures and vulnerability of this population. This logic has not extended to residential care, assisted living, and the various other forms of licensed and unlicensed supportive housing and group quarters. The absence of uniform definitions for these housing and living quarters among states and within the federal government, and even within the housing industry further complicates comparison of the studies that are done.

The term supportive housing is used in this paper to be inclusive of all licensed housing for the aged and disabled, and those unlicensed facilities offering meals, maid service, and at least some level of assistance with activities of daily living (e.g., bathing, dressing, medication supervision, and transferring assistance). The definition of supportive housing expressly excludes institutional group quarters (e.g., nursing homes, mental health hospitals). This more general term is used for two reasons. The first is to have a term that is broader and more neutral than terms like “assisted living” or “residential care” which, although varyingly defined in state statutes and the published literature, nevertheless connote a specific type of housing in the minds of the reader. The second reason for using a more general term is to address a definitional ambiguity in the US Census living quarters classifications. The census, and many national surveys, attempt to distinguish housing units (e.g., single family houses, apartments, flats, mobile homes) from noninstitutional group quarters. This distinction has proven operationally illusive, and has resulted in a substantial under enumeration of the population in such housing.<sup>1</sup>

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<sup>1</sup> Noninstitutional group quarters as defined by the census includes both unlicensed facilities (e.g., rooming homes, communes) and licensed facilities (such as halfway housing, homes for the aged and disabled, licensed residential care, board and care, adult foster care, and the many other labels used by states to defined licensed housing). A fundamental problem with this operational definition is that it requires census enumerators to classify a housing unit as group quarters (or not) based on consideration of whether it is a licensed facility; and, if unlicensed, on the

The seriousness of the classification problem is illustrated by the 1990 Census. This national enumeration shows about 99,000 persons age 65 or over living in “other (noninstitutional) group quarters” (Bureau of the Census, 1992). This count contrasts markedly from inventories of licensed housing facilities, which report more than half million persons living in licensed “board and care” homes for those age 65 or more (Hawes, Wildfire, Lux, 1993). Further, the census enumeration does not distinguish another million persons of all ages living in unlicensed facilities offering some level of assistance (US DHHS 1982) in the early 1980. In short, the census definition of noninstitutional group housing has proven problematic, in part because of ambiguity in differentiating group housing from other forms of supported living, and because licensing status affects how a building and its residents might be classified. Further complicating matters is that licensing requirements vary over time and among states.

What we know about supportive housing operators and residents has generally come from case studies and convenience samples of facilities and residents (see for a review Newcomer, Lee, Wilson, 1996). Typically, studies have been limited to one or perhaps a handful of purposefully selected states. Even major “national studies” (e.g., Hawes, Rose, Phillips, 1999) and General Accounting Office studies (e.g., US GAO 1999, 1997, 1989; US DHHS 1982; US House of Representatives, 1989) have used facility and resident samples which are often not generalizable to either national or state-wide populations. Industry sponsored surveys (e.g., American Seniors Housing Association, 1999), while increasing in number and frequency, are compromised by low response rates and samples limited to association memberships. State-wide supportive housing surveys are conducted from time to time, but not systematically across the nation, and not with regularity within states (Mollica, 2000).

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features and services available and the number of unrelated individuals sharing these features. Assisted living facilities illustrate the classification dilemma. If an assisted living facility is licensed the units and their residents might be assigned into the noninstitutional group housing classification. If the same physical facility is unlicensed (and with a kitchenette in each individual unit), then it might be considered to be an apartment. Other examples of living quarters subject to classification ambiguity include supervised apartments, retirement hotels, and retirement communities, residential care facilities, and board and care.

One consequence of these limited surveys and data systems is that health status, functional and cognitive abilities among supportive housing residents are not well documented across the country. Knowledge about staffing, services, operational performance, and the fit between the capability of residents and the facilities in which they live is similarly limited. The following sections provide a brief review of selected governmental survey and administrative record systems and suggestions of how these could be adapted to fill many policy and quality of care information gaps relative to supportive housing. The intention is to stimulate consideration of means of meeting these information needs building on existing resources. The review does not consider industry sponsored or other surveys that have been developed to support investment and business decisions within this industry.

#### National Population Surveys

National housing and health status monitoring systems, such as the National Health Interview Survey and the Medical Expenditure Panel Survey, have not kept pace with the evolving forms of supportive housing and noninstitutional group quarters, including those of residential care and assisted living—terms that are used interchangeably throughout this paper. There are four problems in particular with national population surveys. One is the limited measurement of disability in many national surveys, such as the US Census and the American Housing Survey (Adler, Clark, DeMaio, Miller, Saluter, 1999).

The second problem is that the samples used in most national surveys of population health characteristics (including the National Health Interview Survey or NHIS) are intended to produce estimates of the community dwelling population. Because of this, sample designs exclude persons in “non-community settings.” Excluded dwellings include institutions such as nursing homes, mental health hospitals; and noninstitutions such as rooming homes, communes, homes for the aged and disabled, halfway housing, licensed residential care, and other housing or living quarters defined as group housing. Assisted living and retirement housing may be included if the survey enumerators classify the housing unit as independent apartments or excluded if they are licensed and considered to be noninstitutional quarters. Persons in these “ineligible” or out of

scope living quarters are not included in the survey. Even surveys such as the Medical Expenditure Panel Survey (MEPS), which include samples of the nursing home population, fail to expressly sample persons in supportive housing.

A third problem is that most surveys (some exceptions being the MEPS, the Medicare Current Beneficiary Survey or MCBS, and the Health and Retirement Survey) provide a cross sectional description of the community population, rather than tracking the sampled individuals or households over time. Without longitudinal data there is no measurement of changes in health status or functional support, and consequently no information on how changing status may be related to one's living arrangements, or of the consequences that a misfit between needs and supports may have on the likelihood of moving, and no information on how the living quarters themselves may be changing.

The fourth, but more easily resolved problem is that the living quarters classification codes used by both population surveys and the panel studies do not distinguish the level of services provided by the housing facility, or whether the facility is licensed as a form of supportive housing. Operational definitions of supportive housing that are separate from whether the facility is licensed or not helps address the complication that states vary in their licensing criteria.

The living quarters classifications differentiating independent housing from group housing, as in the opening discussion, basically originate with the US Census (McCoy & Conley, 1990). Many national surveys of the aged and disabled population build off of these classifications in their sample design. The net result is that both national and community level information about housing and living arrangements essentially ignores or misclassifies the population living in noninstitutional supportive housing. Special surveys are sometimes conducted for nursing homes, but there is no parallel process to obtain or compile information on those living in the other long term care quarters used to define supportive housing in this paper. The magnitude of the misclassification problem was reported earlier as being at least 400,000 aged living in licensed housing. Many more persons live in unlicensed forms of supportive

housing. These individuals are also subject to classification error in any survey using Census living quarters definitional criteria. With such error rates the existing census distinctions of living quarters are unreliable for those interested in tracking the population in supportive housing (noninstitutional group housing and otherwise). A further problem is that tabulations of the population in specific types of such housing (e.g., assisted living or any licensed housing) are not currently possible due to both definitional problems, even if enumerator classification error was resolved.

At least six of the more than 75 national and catchment area surveys have the potential to provide national estimates on populations in supportive housing and to monitor changes in these living quarters. None of these currently do. A full listing of these data sources, including information on the sample size, geographic cover, frequency, and sponsoring agency is available from the authors (also see Newcomer & Benjamin, 1997 for a review of all these data sets)

- The National Health Interview Survey (NHIS) is a nationally representative household survey conducted annually by the Census Bureau for the National Center for Health Statistics, part of the Centers for Disease Control and Prevention (CDC). This survey provides an overview of the general health and health care use in the civilian, noninstitutionalized population in the United States. The NHIS excels in its definition of health and disability status, but it has an inadequate sample frame for the disabled population and lacks an adequate categorization of specialized housing and services. The Disability Followback Survey to the 1994-95 NHIS addressed these issues for this one sample, but problems in the “non-institutional” sample frame and in the living quarters classifications continue within the NHIS more generally.
- The Decennial Census collects information on basic demographic and housing characteristics of the US population. This survey produces data for every community and its households. The survey’s living quarters classification need modification to more accurately delineate the various forms of supportive housing. Further, separate

tabulations of the supportive housing units and households are needed. A third problem is that the survey does not collect substantial information on health or disability status.

- The American Housing Survey (AHS) is designed to generalize to selected metropolitan areas as well as nationally. It samples housing units rather than individuals. The housing units are resurveyed periodically to record the status of the living quarters and information on the occupants. Persons who have moved out are not tracked. The AHS is conducted by the Census Bureau for the Department of Housing and Urban Development (HUD). Living quarters included in the survey largely follow the procedures of the NHIS in defining eligible and ineligible living quarters. Three fundamental modifications are needed. One would be to expand the group housing sample to a size large enough to permit a separate analysis of residential care, assisted living, and other forms of supportive housing. Related to this, refinement of the group housing and supportive housing living quarters typology is needed. Finally, measures to identify functional and other disabilities of the residents, and to characterize the services and resources available in the housing units are needed. Beginning with the 2005 national American Housing Survey (AHS), the Census Bureau and HUD will be supplementing the AHS with a sample of assisted living units. The operational definition of supportive housing to be used and physical and cognitive function measures that might be included in the survey instrument have not yet been fully determined.
- The Medicare Current Beneficiary Survey (MCBS) is an on-going multipurpose survey of approximately 12,000 Medicare beneficiaries, stratified by six age cohorts. It is conducted by the Centers for Medicare & Medicaid Services (CMS: formerly known as the Health Care Financing Administration or HCFA). The MCBS is limited to Medicare recipients and therefore excludes a significant portion of the disabled population. Among other things the survey profiles the health, disability, and some housing and health care service utilization data—tracking individuals over three years. The housing categorization suffers from definitional inadequacies common to the NHIS, but the

sample is selected independently of living quarters. This permits this survey to have independent living, group housing, and institutions all represented. Sample sizes in the group housing and institutions are small and necessitate oversampling to have good statistical reliability.

- The Medical Expenditure Panel Survey (MEPS) is intended to provide a foundation for estimating the impact of changes in payment sources and insurance coverage on different economic groups. Impacts include health care use and spending. The survey is sponsored by the Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) and consists of four components: households, nursing homes, medical providers, and insurance providers. The household survey uses the NHIS sample design, therefore it excludes the population in supportive housing. There is, however, a separate nursing home population sample. Measures of functional ability are present.
- Health and Retirement Study (HRS) is a longitudinal survey among a sample of persons age 50 and over. It is intended to explain the antecedents and consequences of retirement, examine the relationship between health, income, and wealth over time; and how the mix of economic, family and program resources affect key outcomes, like retirement, health declines, housing moves, and institutionalization. The survey is sponsored by the National Institute on Aging. The baseline household survey excludes the population in group housing housing as well as those in nursing homes. Persons making housing changes subsequent to baseline are tracked into their new residences, including nursing homes. The classifications for housing do not distinguish basic forms of supportive housing. The survey with a sample of about 20,000 persons is large and includes an over sample of hispanic and Black individuals. However, given the survey's inclusion criteria, these data are useful only for providing estimates of the attributes of those who move into supportive housing, not for profiling the population of supportive housing residents.

#### Nursing Homes

Both the National Center for Health Statistics and AHRQ sponsor nationally representative surveys of nursing homes and nursing home residents. These have been conducted irregularly since the early 1970's, but they provide information on facility services, staff, and residents attributes. They also offer some information on the living arrangements of individuals prior to nursing home entry. Comparable surveys for supportive housing could be modeled after these, but both surveys have important limitations relative to the perspective of the current paper. Namely, they only map that portion of the supportive housing population that enters nursing homes. And secondly, they offer national as opposed to local area information on this. Two data sources are available from CMS that effectively resolve the geographic and irregularity limitations of the national surveys.

These data bases are the On-Line Survey, Certification, and Reporting System (OSCAR); and the Resident Assessment Instrument (i.e., RAI). OSCAR data are available for all certified nursing homes in the US. The data include provider information (including facility characteristics and staffing), aggregated information on the facility's resident characteristics, and health survey deficiencies. These data are collected during annual certification surveys by state contracted agencies. The RAI is composed of three elements, one of which is the Minimum Data Set (MDS). The MDS measures a nursing home resident's functional abilities, medical problems, and emotional states (such as depression and behavior problems). It is collected on all residents at or near the time of admission, upon readmission from a hospital, or if there is a significant change in status, and quarterly. The MDS is specific to each patient. MDS data are used for care planning, quality measurement, and increasingly as a basis for case-mix reimbursement.

Beyond these uses, MDS data could quantify or identify residents moving into nursing homes from both licensed and unlicensed housing facilities, or those being discharged to such facilities. Targeted diagnoses (e.g., skin ulcers, nutrition, dehydration, injuries, drug or medication poisoning) as well as functional and cognitive conditions that were present at the time of admission to a nursing home could be used as indicators. Distinguishing direct admissions to nursing homes from among those in residential care or other supportive housing

(versus transfers from hospitals) could provide a reasonably complete picture of inpatient stays associated with breakdowns in the chronic care delivery in the community as well as in supportive housing.

Another application would be to use the MDS aggregated at the county or community level to track changes in nursing home case mix, perhaps subsequent to changes in state long term care policies (e.g., nursing home and assisted living reimbursement rates, utilization controls) or as local conditions change (such as in the supply of home and community based care, assisted living/residential care). Aggregated MDS information has been used to compare case mix differences across states and counties and to assess relationships with local service supply factors (like residential care beds) and benefit eligibility (e.g., Newcomer, Swan, Karon, et al., 2001).

#### Area Resource File

Area Resource File (ARF), is a compilation of census and other county level data assembled by the Bureau of Health Professions, Health Resources and Services Administration. This is maintained as a county level data base, and updated annually. Included among the data elements are hospital and nursing home beds, the number of physicians, nurses, and other professionals, hospital discharges, population counts with some age and gender tabulations. This data set does not contain home and community based care utilization or supply. From time to time efforts have been made to include information on the supply of “personal care” homes. When used, the personal care information was obtained from states, and relied on state definitions for these facilities. Because of an absence of a uniform definition the enumeration compiled underenumerated and misclassified both licensed and unlicensed group facilities across the county. Supply counts even varied from year to year in some states. Application of a common and inclusive definition across all states could solve many of the limitations in this data set, assuming that states would then follow through with an accurate classification and enumeration.

The availability of within state data on service supply would be valuable for those interested in identifying under and over served communities, and in comparing the distribution of alternative services within and across states and how these patterns change as policy and other environmental factors change.

#### Hospital Discharge Abstracts

Hospital discharge abstracts provide another administrative data set that could be adapted to provide client-level indicators of problems in the long term care system. More than half the states compile hospital discharge abstracts from virtually all hospitals in the state, regardless of patient age or payer. The tracking of hospital discharges associated with hospital and emergency room use (perhaps stratified by such conditions as skin ulcers, malnutrition, dehydration, injuries, drug or medication poisoning) could be used as an indicator for problems in long term care. For such an application information connecting the hospital patient to their address or location prior to the hospital admission is needed. Presently, discharge records are much better at indicating the post discharge destination than in identifying where someone came from, although a housing or living arrangement field is available on the abstract. The definitional problems associated with supportive housing discussed previously in reference to other data sources also apply here. With such problems resolved, incidence rates of the targeted discharges could be estimated and reported by community. These data will have a time lag of up to two years, but they have the potential of providing a barometer of delivery system functioning over time.

An alternative to the discharge abstract data is an NCHS sponsored National Hospital Discharge Survey. It is conducted among a nationally representative sample of patients discharged from non-Federal short-stay (<30 days) and general hospitals. This survey can be analyzed in the manner suggested for abstract data, but with the limitation that data cannot be aggregated at the community-level.

#### Medicare and Medicaid Claims

Data systems based on service recipients, such as the above, have the important limitation that they provide end point information only. Getting beyond that to broader changes in the

delivery system may be desirable. Such work could most efficiently be done by prospectively tracking samples or populations. For example, what is the health care use among supportive housing vs. nursing residents, vs. home and community based care recipients? How do utilization rates, or the types of health system encounters vary pre and post particular policy changes? A source for this information is Medicare and Medicaid claims compiled by CMS. This approach could be either patient specific or anonymous. In the later situation a housing location identifier would need to be added to claims records. Vendor numbers could possibly be adapted to facilitate this. With such identifiers, claims could document the cases living in licensed housing (or other supportive housing of interest), monitor their diagnoses, the procedures/treatments being used, and health care utilization in other settings such as nursing homes and hospitals. Similar data sets could also be organized for recipients of home and community based care programs, those in nursing homes, or other settings.

One major limitation to these data is that managed care systems and other capitation payment arrangements are not fully included in existing Medicare data systems. Within capitated managed care individual procedure bills are not submitted for payment as they are in fee for service reimbursement. How well Medicaid claims reflect co-payments for care, and care uncovered by Medicare in these records is not fully documented. The level of managed care membership among those in residential care is not known, but it would be expedient to limit the use of claims to fee for service recipients.

#### Expanding Licensing and Accreditation Survey Content

Residential care and other forms of licensed housing generally receive annual to tri-annual relicensing/recertification visits to verify ownership, staffing, and various service features reported on the facility licensing application. Existing state annual surveys of facilities and the emerging industry-based accreditation processes (that will also accumulate this type of information) lend themselves to an “OSCAR-type” data system for licensed housing. Such a process could use the annual “visit” to collect further data on staffing and operator provided information on resident characteristics. Deficiencies could also be recorded, as is done in

OSCAR, but this not an essential feature for the purposes being discussed here. A partnering between state and industry accreditation is yet another variation on this approach. Data from this system could be compiled into a national data system such as the Area Resource File. This would permit trend analysis within communities, comparisons among communities or among states. Such data could also be used as a basis for consumer-oriented information systems.

#### Long Term Care Screening Data

The newest data system is one being developed with implementation of Medicaid reimbursement for assisted living/residential care. With reimbursement has come housing preadmission assessments. These help determine the level of care and or payment that will be reimbursed. Assessment data systems are usually limited to those eligible or expected to be eligible for Medicaid. Compiling this resident information, organized by facility produces basic data on resident attributes at time of admission. Compiling data on the continuing case mix, such as from annual reassessment is also likely . State interest in effectuating screening systems has contributed to an interest in the development and testing of MDS-like systems for use in assisted living/residential care. These or any other uniform data systems have uses beyond risk-adjusted reimbursement rate determination. The data bases can also be used to monitor changes in case mix, and rates of change in health and functional status within the population, as well as for quality indicators for the facility. Generalizability of these analyses are limited if assessments do not extend to the all-payer population.

#### Conclusions

State governments have the infrastructure to monitor changes in licensed supportive housing facility and staffing characteristics, but recording systems have not been developed that take full advantage of information that is routinely collected. The monitoring of resident characteristics and the outcomes of their care is much less developed. Industry-based accreditation processes offer the potential to complement state monitoring systems, but they too presently do not include resident-level information. Implementation of Medicaid waiver reimbursement programs for residential care/assisted living is stimulating the development of

information systems connected to eligibility and needs determinations. However, these processes largely ignore private pay residents. Also ignored are unlicensed supportive housing facilities. Population survey and administrative data systems do not currently fill many of these information gaps. All the major population surveys either systematically exclude the population living in licensed or group housing or the sample size of such facilities is too small for reliable analysis. Administrative records usually do not code the beneficiary's type of housing. The absence of appropriate data systems, and the trend data that might be derived from them, greatly impairs the ability of government, industry, and consumers to monitor how changes in public policy and market factors effect case mix, service supply, competition, and the operational performance of the supportive housing industry.

This paper has explored the components of various governmental data systems that might be modified to help fill important information gaps about the supportive housing industry and the population it serves. Resolution of these information limitations is important to the industry and to policy makers for monitoring changes in provider supply, consumer demand, industry performance; and for long range planning. Following are several recommendations offering practical options that build-on existing national population surveys and community-level administrative data. These recommendations are concerned with policy and quality assurance considerations. These options are not mutually exclusive. Multiple federal and state agencies are involved in compiling data on population health, housing supply, service system use. All will likely need to be involved in the creation of appropriate and cost effective data systems for the supportive housing industry.

Recommendation 1. Existing national population surveys such as the National Health Interview Survey and the American Housing Survey should be modified so that they can provide national information on resident and facility characteristics among the population living supportive housing. (As noted the AHS is being modified effective in 2005 to begin including some of the assisted living/residential care housing, although the sample design and measures are not fully determined.) Four modifications in particular are needed. The first, the sample design used by

these surveys has to be expanded to expressly include and/or to over sample persons living in licensed housing and selected supportive living quarters when not licensed. Related to this, the living quarters classifications used to include and exclude housing from these surveys have to be refined to eliminate the housing misclassification errors common in today's surveys. Among other things, these classifications should identify and distinguish assisted living, residential care, and other specific types of licensed housing. Third, data tabulations and public use data files from these surveys should distinguish between the population and facility characteristics of community housing (e.g., single family homes, apartments, flats) and those of supportive housing (e.g., licensed facilities, facilities with services if unlicensed). Fourth, there should be common living quarters classifications used among the various annual surveys, and these should be consistent with the living quarters classification used in the panel surveys (e.g., Medicare Current Beneficiary Survey, Health and Retirement Survey) that track individuals over time, regardless of changes in housing.

Recommendation 2. Data collected by licensing and certification processes should be expanded to become the basis for a community level information system on supportive housing. Community-level data are an important supplement to national population data. Such information can be used to monitor community trends, inter community variation, and aggregated to provide statewide information. Such data systems can be effectuated by expanding relicensing/recertification processes to obtain and compile information on facility characteristics, staffing, and operator or client record-based information on resident characteristics. This process could be implemented by state regulators, industry self-accreditation, or jointly by the governmental and accreditation bodies. These data systems produce an elaborated provider inventory and can serve at least two other practical functions. One would be a consumer-oriented directory of providers, the second would be incorporation into a national data set such as the Area Resource File. Such information could be useful for state and local long term care planning, and in monitoring provider and consumer characteristics over time, particularly as changes are made in reimbursement, benefit eligibility, and the supply of alternative long term care services.

Resolution of the differences among states in their licensing and housing terminology will help improve the consistency of these data across states.

Recommendation 3. Quality assurance systems are a third type of data. Proposed here is an approach that takes advantage of existing administrative systems to provide trend information on the quality of care in supportive housing and service systems. The information could come from hospital and emergency room use, nursing home placement, and adverse events or deficiency citations. Both claims and hospital/nursing home/ER visit surveillance (or hospital discharge abstract) systems could be used for these purposes. For planning and comparative analyses, rates of these events could be developed by facility or by community and tracked and compared over time and among communities to identify trend conditions and relative performance.

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