

CALIFORNIA PATHWAYS/ MONEY FOLLOWS THE PERSON

FINAL REPORT

Contract # 03-75891

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Chapter 1
Introduction

A Supreme Court decision and federal legislation both support the provision of the least segregated care option for individuals with disabilities, when they need long-term care. The Americans with Disabilities Act (ADA) provides that no qualified individual with a disability shall, by reason of such disability, be excluded from participation in, or denied the benefits of, services, programs or activities, or be subjected to discrimination by any such entity. In 1999, the United State Supreme Court issued its decision in *Olmstead v. Zimring* (119 S.Ct. 2176), in which the court concluded that states are obliged by the ADA to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: 1) the state's treatment professionals have determined that community placement is appropriate; 2) the individual does not object to community placement; and 3) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities.

The Court cautioned that the ADA does not require elimination of institutional settings for persons who choose not or are unable to be treated in community settings and that the state's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited. Under the ADA, states must "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity." (28 CFR 35.130(b)(7)). According to the Court, decisions about whether a modification results in "fundamental alteration" of a program should be based on: "1) the cost of providing services to the individual in the most integrated setting appropriate; 2) the resources available to the state; and 3) how the provision of services affects the ability of the state to meet the needs of others with disabilities."

The Court's decision has increased sensitivity to the possibility that individuals may be inappropriately placed in nursing facilities (NFs) and that some NF residents may wish to return home or to community living. But documented evidence of the number of NF residents affected and the services they would need to transition back to the community is scarce. Most research in this area has focused on individuals who are placed in facilities for Medicare-covered rehabilitation services, with the goal of preventing long-term or custodial stays; many if not most of these "short-stay" residents can clearly live outside of the NF after their rehabilitation. There is a significant challenge to evaluating the efficacy of a diversion program that targets people placed in a nursing home for rehabilitation since many of these people return to the community with the assistance currently available through the nursing home discharge process. The challenge is to separate the additive effects of a new intervention from the relatively high percentage of people who return to the community with existing discharge efforts.

There is less evidence about the success of efforts to transition residents who are past the rehabilitation phase and have resided in the facility for what is considered a "long-term stay" of 90 days or more. A recent nationwide review of transition efforts indicates that these efforts have been problematic with most people transitioned being under 65 and male (Eiken, Steve. Thompson MedStat: Lessons learned from the 1998-2000 nursing facility transition grants October 27, 2003).

History of California Pathways: Money Follows The Person Project:

The Pathways project was funded by grants from the Department of Health Care Services (DHCS) and the Department of Rehabilitation (DOR). The major objectives were to develop or recommend the use of a comprehensive assessment protocol to facilitate relocation decisions and to pilot test an intervention to relocate nursing residents to the community. Three decisions were made in the early stages of the project that shaped project activities.

1. It was decided that existing programs would be used in relocation efforts as opposed to applying for a new section 1915 (c) H-C-B-S waiver. The rationale for this decision was that there was no evidence about how well existing waivers worked and in the absence of such information it would be inefficient to develop a new waiver. Moreover, there was insufficient information on the additional or different needs of those transitioning from nursing facilities upon which to request a new waiver.
2. Nursing home residents in the facility for longer than 3 months, (or those that have completed their Medicare part A services and are slated to stay in the nursing home) would be targeted as opposed to residents who were in the nursing home for rehabilitation services covered under Medicare. The rationale for this decision was that people in the nursing home for rehabilitation were more likely to go home on their own than were long-term stay residents who represent a clear population in need of a relocation intervention. The short stay population represents a group who are excellent candidates for averting nursing home placement but it is difficult to argue that you are relocating people who have not yet been admitted to the nursing home for long-term stay.
3. The preferences of nursing home residents for relocation would be emphasized in the assessment process. The rationale for this decision was the belief among consumer advocates who advised this project that previous efforts to develop relocation assessment instruments over-emphasized medical and functional characteristics and decisions made by assessors.

The first step in the project focused on the assessment objectives of the project, which are discussed next.

A comprehensive assessment protocol to facilitate transition decisions should have two major stages: Stage 1) a preference assessment to identify NF residents who want to transition; and Stage 2) a methodology to identify these residents' service needs and living arrangement options as well as a systematic procedure to translate their service needs into care plans and cost estimates.

We conducted an extensive review of assessment protocols used in California and other states to either prevent NF placement or relocate NF residents to less restrictive living arrangements (see chapter 2). Based on this review and feedback from California stakeholder groups, it was decided that most existing assessment approaches inadequately measure a long-stay resident's preference for transition for two reasons.

First, most preference assessments are embedded in larger protocols that also measure individual characteristics that influence service needs. In other words, preference is not the focus of a "stand-alone" assessment in the protocols we reviewed. This latter point is less problematic

when the entire assessment is administered before the person makes a decision about long-term care placement (i.e., diversion rather than transition). This NF diversion approach is used in several states, among them Washington, Wisconsin, and Oregon. However, assessing preference and service needs at the same time is problematic when the assessment is being used to identify long-stay NF residents who may want to transition to the community. In such cases, it is expensive to simultaneously evaluate resident characteristics that influence service needs and preference when many residents may not want to attempt a transition from the facility.

To fulfill the ADA's intent, preference should be measured among all long-stay residents using a standardized protocol. Ideally, personnel who have no conflict of interest with residents' living arrangement decisions should conduct these preference assessments. All residents who express a desire to transition should then receive further and more extensive follow-up assessments to identify medical and functional characteristics that influence their service needs. A good case can be made that living arrangement preference assessments of persons who are either receiving or being considered for long-term care should be conducted before a more detailed medical or functional assessment is conducted. Preference is arguably the most important factor that should influence living arrangement decisions. Certainly, it has sufficient importance to be a "stand-alone" measure.

The second problem with existing approaches to preference assessment is that none of the interview protocols were designed to increase the probability that respondents can answer questions in an informed manner. In many cases, the questioning format used seems to assume that residents have already, prior to the interview, expressed a desire to transition. In other cases, interviewers are not provided with standardized preference questions. In such cases, the identification of NF residents interested in transitioning depends on the interviewer's bias or skills. In general, existing protocols grant interviewers wide flexibility in formulating questions to ask.

This informal and indirect approach to preference assessment could be problematic because many long-stay NF residents may have reduced expectations for care or a poor frame of reference for evaluating alternatives, either of which might lead them to provide uncertain responses to transition questions. Interviewers in turn might interpret these responses as a preference to remain in the facility.

In light of the shortcomings of existing protocols, we designed an assessment tool that aims to increase respondents' awareness of community services and living arrangement options before they make a preference decision about their living arrangement. The protocol, the California Nursing Facility Transition Screen (CNFTS), is designed as a "stand-alone" assessment that can be conducted with all individuals, both those residing in NFs and those who are considering NF placement. The protocol features a standardized questioning format designed to minimize interviewer bias and subjective judgment. In Chapter 3, we discuss in more detail how and why this preference assessment protocol is recommended for use in California to facilitate NF transition decisions.

It should be noted, however, that this protocol does not fully evaluate a resident's service needs or the potential costs of providing care to the resident in the community. In this regard, we

recommend that one of the assessment tools currently in use be further tested with residents who are identified through our protocol as wanting to transition (see Chapter 2). Chapter 8 presents our recommendations for implementing a comprehensive assessment protocol consistent with the ADA's intent. The approach we recommend is intended to increase the probability that resident preferences are considered when making decisions about NF placement and community service use.

Chapter 2
Review of Assessment Protocols

This chapter describes and compares assessment protocols currently being used to facilitate decisions about long-term care placement in both California and the nation.

Selecting Protocols for Review

We solicited feedback from stakeholders regarding both the selection of the assessment protocols for review and the evaluation criteria for comparing them. The list of assessment tools and the evaluation criteria were distributed via e-mail to state policymakers and representatives from aging and disability networks. The distribution list also included the project's advisory council members as well as members of the Olmstead advisory council. After receiving feedback on which instruments to include, we obtained copies of the selected assessments and their instruction manuals from either the Internet or administrators from each state or program. This process resulted in the selection of 13 protocols for review. We list them below under four broad categories:

1. National Assessments:
 - Minimum Dataset 2.0
 - Minimum Dataset for Home Care (also known as RAI-HC)
 - Outcome and Assessment Information Set (OASIS)
2. Statewide California Assessments from:
 - Multipurpose Senior Services Program (MSSP)
 - In-home Supportive Services (IHSS)
3. Local California Assessments from:
 - California Assisted Living Pilot Project
 - San Mateo's Uniform Assessment Tool
 - Santa Rosa's Nursing facility Transition Tool
4. Model Assessments from Other States:
 - Michigan's MI-Choice Waiver Program assessment
 - Texas's Inventory of Community Service and Support Needs for Nursing facility Transition
 - Oregon's Client Assessment and Planning System tool
 - Wisconsin's Long-term Care Functional Screen
 - Washington's CARE uniform assessment

The Minimum Data Set (MDS) was selected for review because of its reported reliability and validity. Additionally, data collected from MDS assessments are widely used by the Medicare program and many state Medicaid programs to determine provider reimbursements as well as to monitor the quality of care provided to nursing facility residents and home care clients. Similarly, the OASIS instrument is widely used by home health agencies to meet CMS's standardized reporting requirements.

MSSP and IHSS assessments were included because they are used throughout California by many aging and disability programs and services. San Mateo, Santa Rosa, and the California Assisted Living Pilot Project have developed innovative assessment tools that foster system integration, nursing facility transition, and the determination of level of need, respectively. The five state assessments (used in Michigan, Texas, Oregon, Wisconsin, and Washington) were selected because they are recognized by the literature as exemplary. Appendix A presents a description of each protocol.

Criteria to Evaluate Assessment Tools

Underlying our selection of evaluation criteria is our belief that it is important to examine not only the assessment itself but also the tool's purpose and assessment process as well as whether the tool is part of a larger process to facilitate service integration. For example, we wanted to know whether a protocol could be used with different subject populations or for multiple purposes such as reimbursement and care planning. We also consulted a report by Jennifer Gillespie of the National Academy for State Health Policy entitled "Assessment Instruments in 12 States," which facilitated our selection of the following evaluation criteria:

- Context and Purpose of the Assessment Tool: How is the tool used?
- The Assessment Process: How are the data gathered and used?
- System Integration: Is the tool used within the context of a system? Is that system integrated across populations and programs?
- Content: Are the following key elements covered?
 - Individual Preference
 - Memory/Cognition
 - Social Support/Living Arrangements
 - Physical Functioning
 - Diseases/Conditions
 - Medications
 - Housing/Home Environment
 - Transportation
 - Service Utilization

Comparing the Protocols

We created a grid to compare the protocols on each evaluation criterion. The grid's first section provides an overview of each assessment, including its purpose, administration, and role in system integration. To complete this section of the grid, our research team collected information from key administrators via telephone interviews, from background materials that accompanied the assessments, and from assessment manuals.

The grid's second section analyzes the content of the assessment tools. Initially, we based this section's categories on the InterRAI-HC. As other assessments were reviewed, we added any new items not covered by the InterRAI-HC.

Affirmative responses were used if an assessment appeared to measure the category, regardless of how the items were measured. We also noted on the grid the method for measuring each item (e.g., self-report, assessor observation, caregiver/family report, supporting records or documentation, performance-based) and coding responses (e.g., scale, yes/no, or open-ended).

To improve the accuracy of the grid and ensure inter-rater reliability, administrators or key personnel from each program or state reviewed the grid responses for their assessment tool. The research team then addressed any discrepancies between the original coding and feedback from the administrators. Appendix B illustrates the grids.

Key Findings

1. The Context and Purpose of Assessment Tools

The grid analyzes three types of assessment tools: those used solely for assessment purposes; those used in the context of a specific program, and those used as part of a larger system of care. The assessment tools have limited functionality on their own, outside the context of a program or system that turns the raw assessment data into usable information for eligibility determination, care planning, quality assessment, or reimbursement.

The MDS, MDS for Home Care (MDS-HC), and OASIS are examples of tools used solely for assessment purposes. The MDS is a federally mandated, standardized tool used to assess all residents in nursing facilities that accept Medicare or Medicaid payments. The MDS is part of a larger assessment protocol, which includes triggers that identify specific care needs and Resident Assessment Protocols (RAPs) that suggest approaches to addressing those needs. By itself, the MDS is an assessment instrument that is useful for developing care plans. Within the context of a system, however, it can be used for reimbursement purposes. Specifically, the MDS is the basis for the Resource Utilization Groups (RUGs), which facilitate payment for Medicare-covered skilled nursing care and Medicaid-funded long-term care in many states.

Similarly, the MDS-HC is a stand-alone assessment instrument with triggers and Client Assessment Protocols (or CAPs, which are similar to RAPs). The MDS-HC's functionality is increased when it is automated, which occurs only in the context of a program or system.

OASIS is another mandated tool used to assess all persons who receive home health care from Medicare-certified agencies. In contrast to a comprehensive assessment instrument, this tool focuses on measuring outcomes. OASIS can be augmented by individual home health agencies to facilitate care planning.

Other tools, such as MSSP and IHSS, are designed to be used by programs that target specific populations, and may not reasonably be used for other populations. Similarly, the assessments used in Santa Rosa and Texas are designed for a specific purpose: to determine the health and service needs of individuals who want to transition from the nursing facility into the community.

In its most comprehensive form, an assessment tool can be used within the context of an integrated system. Washington, Wisconsin, and Oregon have each developed their own

statewide, uniform assessment, which determines eligibility, provides authorization, and creates a single point of entry into each state's long-term care system. Findings from these tools are used to develop care plans and are automatically linked to reimbursement levels.

2. The Assessment Process: Automation, Algorithms, and Assessors

An assessment's administration can be automated or paper-based. Automated assessments ensure access to information by multiple providers and allow for the use of a standardized algorithm to synthesize responses. Data from these assessments also can be easily displayed in graphs or analyzed for quality improvement purposes. Washington's assessment process allows data to be scanned or entered directly into a computer and includes software programs that use standardized algorithms to convert raw assessment data into usable information for care planning and reimbursement. On the other hand, the data from paper assessments used in Santa Rosa's and Texas's nursing facility transition programs as well as in IHSS and the California Assisted Living Pilot Project are more difficult to share across providers. Additionally, if funders mandate data reporting, paper-based assessment information may need to be entered into a computer database.

Assessments also vary by assessor qualifications, training requirements, and the use of instruction manuals. Assessors need to be adequately trained so that they understand the importance of adhering to assessment protocols and completing assessments accurately. Training also helps prevent assessors from viewing the work as an additional burden. Training or certification is required prior to using most assessment tools, with the exception of the nursing facility transition tools used in Santa Rosa and Texas. Most assessment tools come with instruction manuals, but these vary in their level of detail. The tools used in Washington and Wisconsin, for example, feature detailed interview protocols and scripts to follow to ensure standardized approaches to interviewing and probing clients and therefore, inter-rater reliability.

3. Systems Integration

Integration may include more than one population, multiple programs, and/or multiple assessments in a defined geographical area (e.g., a county or state). System integration involves the coordination of care across programs and sectors. Ideally in an integrated system, money follows the person—not the program—across community-based and institutional care systems. Such is the case in Washington, Wisconsin, and Oregon. Tools are used within the system to enhance information sharing and reduce duplication. In San Mateo, California, for example, the goal is to integrate programs through information sharing. Building on the MDS instrument, leaders in San Mateo have designed a single assessment tool to be used across multiple programs. The instrument is housed in a single information system to reduce duplication of data collection and to ensure that data is easily shared across programs.

The existence of a system, however, does not imply integration. Michigan's MI-Choice program uses a modified version of the MDS-HC as its core assessment instrument. This assessment is used in the Medicaid Waiver program as well as the Care Management program, a state-funded program that serves clients who meet the functional eligibility requirements of the Medicaid Waiver program but are not Medicaid-eligible. Although this system uses the same

assessment across programs, it does not aim for integration, and the assessment data are not regularly shared across programs.

4. Coverage of Key Elements

Six assessment protocols contain items that measure an individual's preference for living arrangement and three additional protocols assist in the nursing facility transition process, though they do not specifically assess living arrangement preferences. The MDS asks about preference to return to the community and the availability of a support person who is "positive towards discharge." In Santa Rosa and Texas, nursing facility residents are referred to transition programs when they express a preference to return to the community. Therefore, only a few assessment questions in these states' tools address preference; their primary focus is on assessing living arrangement and service needs. Washington's tool features an open-ended, broad assessment of client goals, which can include returning to the community. Assessments used in Oregon and Wisconsin ask about current and preferred living situation. Three assessment tools—MSSP, IHSS, and the ALWPP—are used within programs that facilitate nursing facility transitions but none of these tools contain items that assess individual preference for living arrangement.

In summary, only the MDS explores familial support for an individual's preference for living arrangement. No tool identifies family opposition or any potential difficulties in meeting the client's preference, an issue explored further in Chapter 3. Many of the protocols either failed to provide instructions and specific questions to guide client interviews or suggested that interviewers adopt an informal approach to assessment. We discuss this aspect of the protocols in the next chapter.

All the assessment tools tend to cover similar domains and potential problem areas, including functioning, cognition, health status, medications, social support, and service use. Few tools address issues related to current employment, activity pursuit patterns. Although the assessment tools examine similar domains, they vary in their measurement and coding of responses. For example, all the tools measure activities of daily living (ADLs), but some ask about the person's ability to perform these tasks independently while others ask about difficulty performing the tasks with or without assistance. Furthermore, the mechanism for gathering information varies from tool to tool and may be based on self report, proxy report, assessor determination, or a performance assessment.

At times, assessment items did not fit neatly into our grid categories, thus requiring interpretation. Often our research team debated whether an assessment item really measured a certain construct. For example, we debated whether the MDS measure for "decision making" is the same as the IHSS measure for "judgment." Given this uncertainty, the ratings we assigned to some elements are arguable. Uniform assessment instruments used by all agencies with an interest in long-term care can facilitate standardized definitions and reduce such confusion.

In general, there are fewer differences in the tools' assessment approaches than in other evaluation criteria reviewed in this report. However, the most comprehensive protocols we reviewed for the MDS-HC are those used in Washington, Oregon, and Wisconsin.

Chapter 3

Identifying Residents Who Want to Leave the Nursing Facility (Stage 1 Assessment)

This chapter describes a protocol for identifying resident and family preferences for living arrangement and nursing facility transition.

A comprehensive assessment protocol that applies the principles embodied in the Olmstead decision to long-term stay NF residents must include a valid methodology for identifying NF residents who want to leave the facility and who believe it is feasible to do so if adequate resources are made available. Most of the protocols we reviewed in Chapter 2 measure an individual's preference for living arrangement either before a resident is admitted for a long stay in a NF or after the resident is identified by caregivers as wanting to transition. In addition, the instructions for the protocols that measure preference are rather general and allow interviewers wide flexibility in how preference questions are asked. This approach can lead to inconsistent interview techniques. For example, the MDS protocol, which is used with all long-stay residents, includes a specific transition preference item. However, the instructions to caregivers completing this item recommend an indirect approach toward assessment for those residents who have had a lengthy stay in the facility. The relevant MDS item, [Q] 1.a., reads, "Resident expresses/indicates preference to return to the community." NF staff complete the item by checking either yes or no.

The instructions for this item are as follows:

"For new and recent admissions, ask the resident directly. The longer the resident lives at the facility, the tougher is it to ask about preferences to return to the community. After one year of residency, many persons feel settled into the new lifestyle at the facility. Creating unrealistic expectations for a resident can be cruel. Use careful judgment. Listen to what the resident brings up (e.g., Calls out, 'I want to go home'). Ask indirect questions that will give you a better feel for the resident's preferences. For example, say, 'It's been about 1 year that we're known each other. How are things going for you here at (facility)'."

On the one hand, such indirect questioning may reduce the risk of creating unrealistic expectations. On the other hand, it may fail to identify individuals who want to be considered for a transition program. In this chapter, we present data pertaining to how accurately this MDS item identifies residents who want to transition.

The lack of emphasis on a more direct or active form of preference assessment is arguably defensible if the individuals being interviewed are aggressive and spontaneous in expressing their preferences. For example, patients recently admitted to a NF for rehabilitation will likely have community living arrangement and express a strong desire to return to that living arrangement even if not directly asked about their preference. The danger is that long-stay residents who have become more institutionalized and those who lack viable living arrangement may not be so spontaneous in expressing their desire to live outside the NF. Indeed, many of

these residents may not even believe that an alternative to the NF is possible for them. This latter possibility is considered probable by many consumer advocates who influenced the early design of the preference assessment protocol described in this chapter.

Initial Design and Testing of the CNFTS

Previous efforts in California to design a transition assessment protocol were criticized as being too medically focused, according to initial reports by officials at DHS and DOR, the sponsors of the current project, as well as stakeholder groups who provided initial input into this project's design. The essence of this criticism appears to be the perceived failure of most assessments to adequately measure resident preferences. Such measurement is critical because many people with a strong preference to live outside the NF can do so despite the presence of medical problems that would appear to make community living difficult. The failure to evaluate individual preference means that the resident's medical status is either the primary or the only factor influencing the transition discussion. A related concern is that many residents may not express a strong, spontaneous preference to transition due to their lack of knowledge about community living and service options. Thus, either an informal or indirect approach to assessing preference (such as that recommended in the MDS) may not capture what residents really want to do, but rather what they mistakenly think they can do. Unfortunately, there are scant data available to either support or refute these concerns.

MDS data indicate that between .5% and 12% of residents across all states are rated by NF staff as wanting to leave the facility (see MDS item [Q] 1.a. previously listed). The stakeholders advising this project, however, consider these figures inaccurate, notwithstanding the fact that California is at the top of this range, with 12% of non-Medicare residents over age 65 being rated on the MDS as wanting to transition. Unfortunately, we could find no information about the accuracy of this MDS item; nor could we find other data independent of NF staff reports to indicate how many residents want to leave the NF.

To better gauge the issue, we designed a standardized preference assessment interview protocol for the purpose of identifying how many people want to leave the NF and their preferred living arrangement option. We solicited feedback on this protocol from multiple stakeholders and then field-tested a revised protocol in two NFs. In both facilities, project staff attempted to interview all long-stay residents and their relatives. Resident and family responses were compared to MDS item [Q] 1. a. (Does resident want to leave?) as well as to reports from NF staff, who were asked the following two questions: "What residents do you think want to leave the NF?" and "What residents are good candidates to leave?"

This field test produced several results with immediate implications for designing a nursing facility transition program. Most important are the following preliminary conclusions:

1. In each of the two NFs, 25% and 56% of the resident participants, respectively, indicated a strong preference for transition. Though many advocates may have expected them, these relatively high percentages suggest that demand will be strong for transition efforts and community living arrangement. This raises the question: Are there adequate resources available to meet potential demand for relocation?

2. NF staff did not identify most of the residents who wanted to transition, either through their MDS ratings for residents or in direct responses to the questions posed by our research staff. This preliminary result suggests that resident preferences should be measured independently of the data reported by NF staff.
3. Fewer people who expressed a preference to relocate also thought it was feasible to leave the nursing home even after hearing about housing and service options that might be available. This group of people would very likely need more information or education about relocation issues before more labor-intensive efforts are made to initiate relocation activities. These data clearly indicate the need to measure both preference and perceived feasibility of relocation in the initial assessment stages.

Based on these preliminary findings, the preference protocol was revised and tested in eight additional nursing facilities. It should be noted that the 8 facilities were volunteers and that over 30 homes that were approached refused participation. These difficulties in recruitment underscore the need to develop mechanisms at the state level to assure that all Medi-Cal residents in nursing homes can be accessed for at least a first stage preference assessment.

The data generated from the preference assessments as well as the interview protocol are thoroughly described in the Journal of the American Geriatrics Society (JAGS) January 2008 issue.

Chapter 4
Preliminary relocation results

Relocation results in second project year. During the second year of the three-year contract, 22 residents who believed it was feasible to relocate were referred to one of three community agencies that had agreed to assist with relocation activities. Four residents successfully relocated; most (18) were terminated from further relocation efforts based on difficulties finding housing or the determination by the agency that the resident was not a good candidate for relocation. The criteria used to make these termination decisions are not clear in some cases, which argues for the use of a standardized assessment protocol as suggested in the recommendation section below. Three cases that have been put on hold either because the agency reported they could not work with more residents or the resident was too young to qualify for their services.

Based on these preliminary data several changes were made for the third project year:

1. A transition coordinator was hired by the project to work in three homes and identify residents who have been admitted to the long-term stay portion of the nursing home in the early stages of their placement
2. More systematic procedures to monitor the relocation activities of community agencies were developed.
3. The assisted living waiver, which holds the most promise for working with younger people who have problems locating appropriate housing, will be better utilized since more facilities will presumably be recruited that may serve as housing options.

Chapter 5 *Phase II Study Results*

Phase II of the California Pathways study focused on the intervention process, and attempted to identify which aspects of the methodology worked well and what barriers stood in the way of successfully implementing the program statewide. The study results discussed hereafter pertain only to Phase II, unless otherwise indicated.

Four nursing facilities in Los Angeles County participated. Two hundred fifty seven residents met the inclusion criteria. Of those, 73 residents or proxies declined. Sixty-nine respondents provided reasons for the decline. The majority (78%) related to the intensity of care needs. Six percent were proxies who reported that their relative was happy in the facility and should not be moved, and 3% percent reported that nursing facility placement was the recommendation of the physician. The remainder consisted of residents who declined, and indicated that they were not interested in moving. Seventy-eight residents could not be contacted for a variety of reasons. The remaining 106 agreed to the assessment and were interviewed at least once.

Fifty-three residents (55%) of respondents indicated a preference to relocate, similar to results from the initial field-testing of the CNFTS discussed in Chapter 3. Another finding similar to that in the field-testing, was that fewer people (48) also thought it was feasible to leave the nursing facility.

Thirty-six residents expressed a stable preference to move as defined in the study protocol (see attached JAGS article). This group had a mean age of 73 years and mean length of stay¹ (LOS) in the nursing of 631 days². There were gender differences noticed in this group. The women were older and had a mean LOS more than twice as long as men. They were also more likely to have a proxy.

Twenty-five residents were referred to community agencies to be assessed. This group had a mean age of 72.3 years and mean LOS of 766 days. The average age and LOS for men was 68.1 years and 492 days, while for women these figures were 78.6 years and 1178 days.

Ultimately, nine residents were transitioned, 25% of those expressing a stable preference to relocate. Two of these residents used the assistance of study researchers and agencies to complete the transition. One former resident later requested assistance and was referred to an agency. Four residents transitioned to assisted living facilities, three transitioned home, one transitioned to a homeless shelter and one transitioned to an unknown location. Within the nine residents that transitioned, men had a longer LOS than women (387 and 196 days respectively).

Although 20% percent of those referred had proxy decision-makers, none of those residents transitioned. The transitioned group consisted solely of self-consenting individuals. The self-consenters are likely less cognitively impaired, which is supported by MDS scores for daily decision-making. Six of the nine were “Independent” and the remaining three “Modified

¹ Length of stay calculated from NF admission date to the date the stability interview was conducted

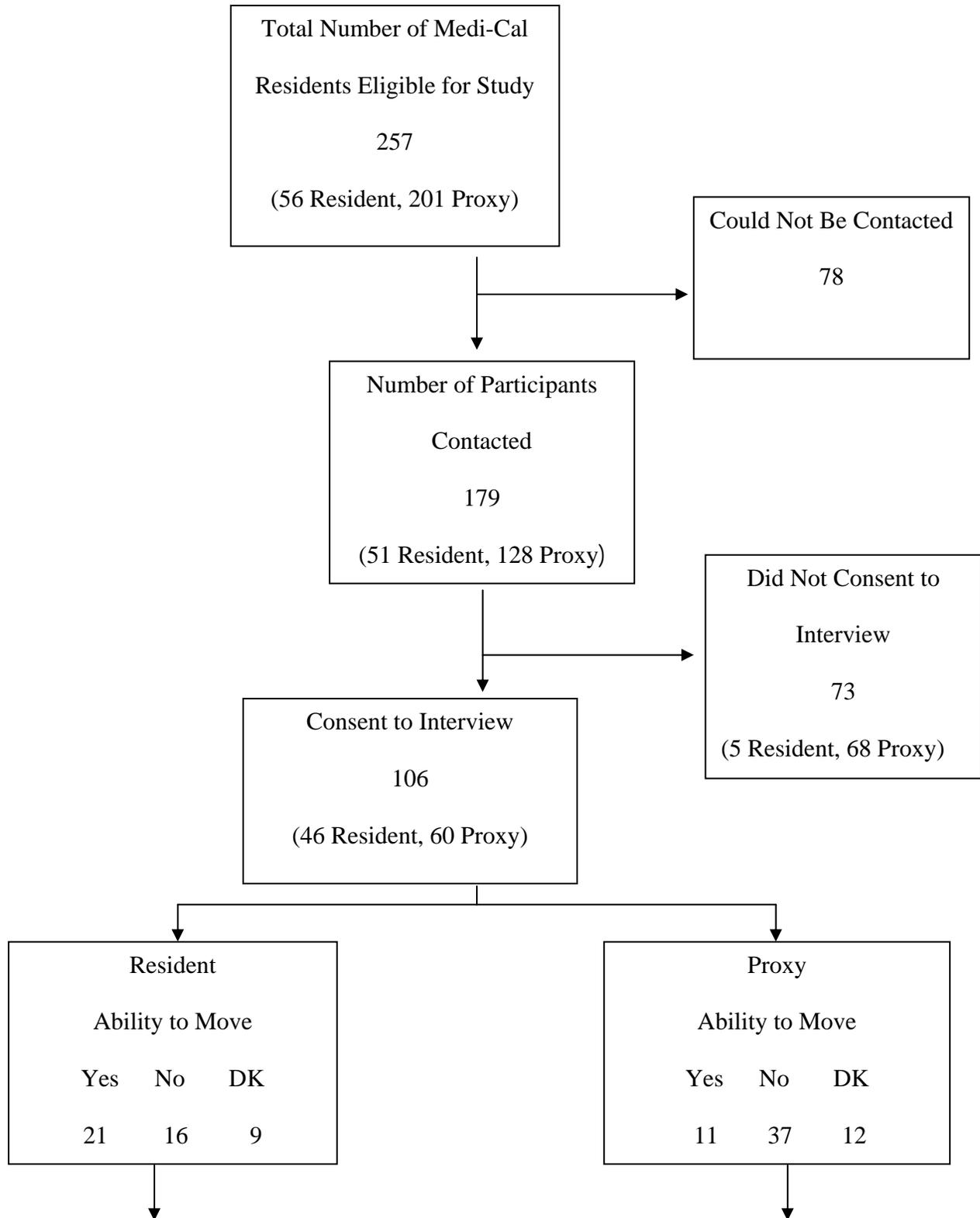
² Age data available for 35 of the 36 residents discussed here, and LOS data available on 34

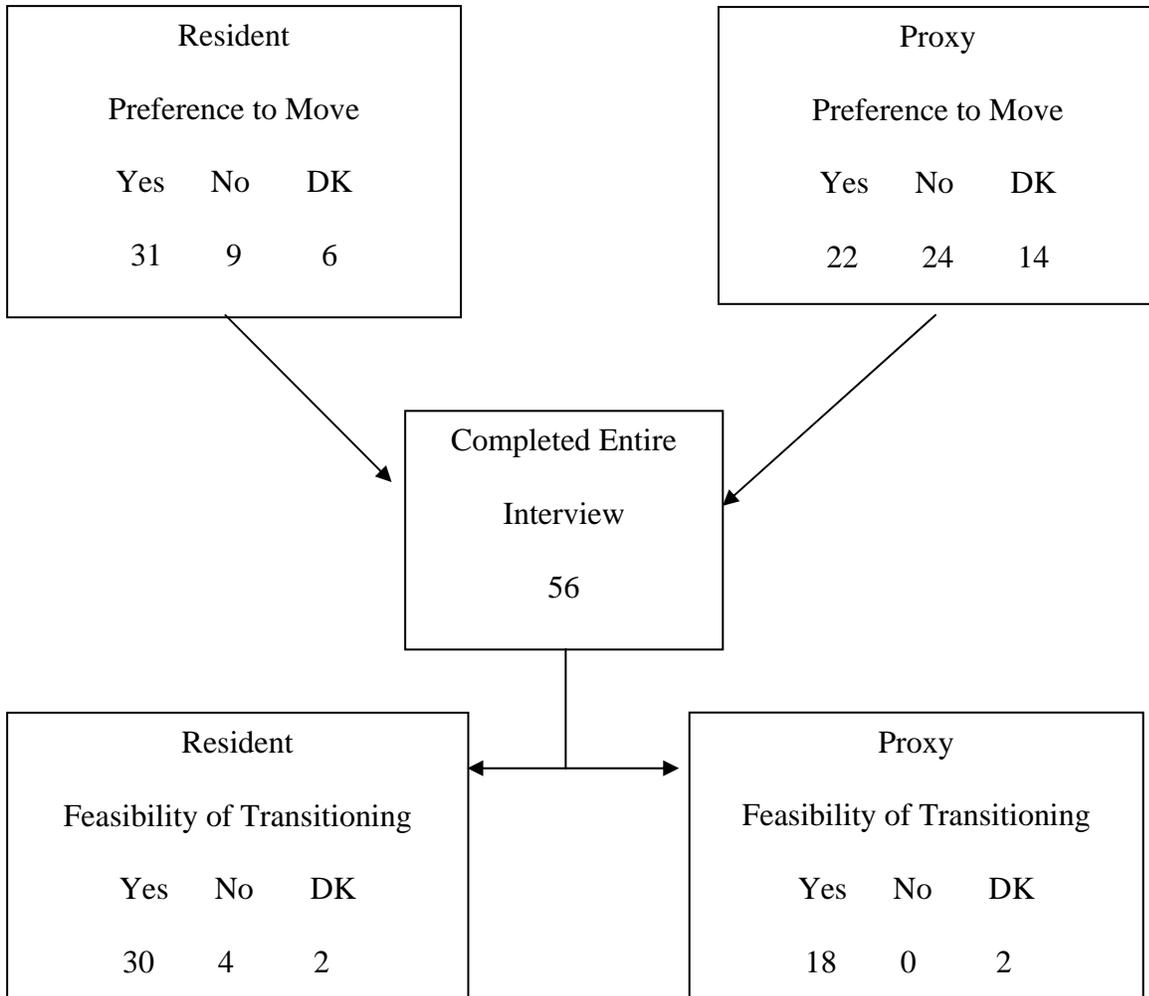
Independent.” But the data are not definitive on this. In the group that was referred but not transitioned eight scored “Independent,” seven “Modified Independence,” two were “Moderately Impaired” and only one “Severely Impaired.”

When further comparing the characteristics of the group that actually transitioned to the group referred to an agency but where transition was not completed, we find another distinct difference. LOS in the nursing facility for the transition group was 323 compared to 947 days for those referred but who did not transition. It appears that the length of time a resident is residing in the nursing facility is an important determinant of whether a person will successfully transition from the facility.

Figures 1 and 2 summarize phase II study results.

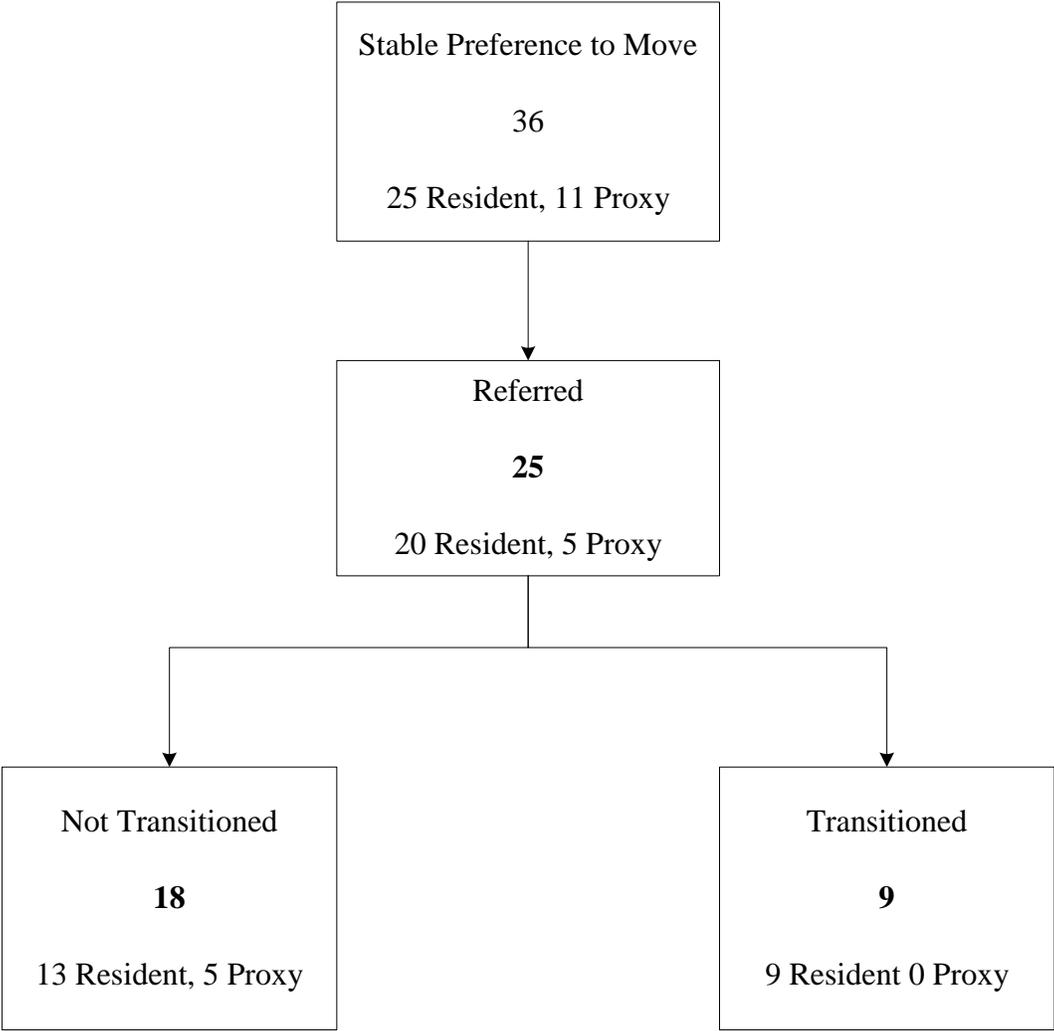
Figure 1. Phase II: Flow of Participants Through the Study and Responses to the Transition Screen





Note: DK= Don't Know

Figure 2. Phase II: Flow of Participants with Stable Preference to Move through referral and outcome



Chapter 6
Time Analysis

Time spent by research staff was recorded in a time-tracking module by recording 15-minute intervals for each activity (contact, consent, interview 1, interview 2, HIPAA, MDS, release, secondary interview, tier ranking, Michigan, summary sheet, referral, agency updates, other, follow-up). These activities were tracked separately for proxies and self-consenters.

Table 1 provides summary data for the Phase II time analysis.

Table 1. Summary of Phase II Time Spent in Hours By Activity and by Group								
Activity Group	Interview Hours	% of total	Referral Hours	% of total	Transition Hours	% of total	Total Hours	% of total
Proxy	108.75	60%	15	23%	5.25	14%	129	45%
Self-Consenter	72.75	40%	50	77%	32.25	86%	155	55%
All Cases	181.5		65		37.5		284	

The total amount of time spent by researchers during Phase II was 284 hours (129 hours on proxies and 155 hours on self-consenters). While the total amount of time spent on proxies was less than self-consenters, it quickly becomes apparent that the per-resident time is much higher for proxy cases when conducting interviews. The majority of hours spent interviewing, for residents with proxy representation. When reviewing the number of interviews conducted, this initially appears proportionate. However, this analysis does not capture the time used up in delays caused by repeated contact attempts, or time spent waiting at each step in the process. Additionally, when looking at the outcome of the effort there is also a difference. Residents with proxy representation made up only 30% of the total number of those indicating a stable preference to move so the time required to bring a proxy resident to the stability phase is nearly three fold greater than for a self-consenting resident. Time spent on referrals was nearly identical for the proxy and self-consenting groups, and maintained a ratio closely approximating the distribution of cases between proxies and self-consenters.

It is important to note that the time captured by researchers does not reflect the time spent by community agencies and their staffs to assess residents, and to participate in the transition process. It is not known precisely how many hours this will add on a per case basis, but based on a review of a limited number of cases it is estimated at a minimum to be in the range of 40 hours per case. DHCS should factor the time and the related costs for these services.

Chapter 7
Barriers Identified During the Study

Several barriers were encountered during the study, and these were found at each stage of the process. They are summarized below.

1. Barriers to Identifying Transition Candidates

- a. Recruiting Nursing Facilities to participate. The goals of the nursing facility are not necessarily in-line with study goals. And even the internal dynamics in the facilities can cause barriers. Facilities would need to be required to participate with DHCS so this barrier will not exist.
- b. Identifying self-consenters. Study protocol dictated the reliance on financial responsibility, as indicated on the facility chart face sheet, to determine whether or not a resident was self-consenting. There are weaknesses in this approach, including the inaccuracy of the information on the face sheets. Additionally, financial responsibility is not a reliable method of determining if a person is a reliable informer and /or has an authorized proxy health care decision maker.

2. Barriers to Assessment

- a. Language. Researchers encountered some non-English speaking residents and needed to arrange for translation.
- b. Hospitalization. Sometimes hospitalization, death or other issue arose prior to conducting either the first assessment or the stability assessment.
- c. Scripts: “Selling” the program. Not surprisingly, proxies were wary of the phone calls from researchers. These individuals are not familiar with the Olmstead decision and the efforts occurring as a result. Being approached in a manner akin to a “cold call” made success more difficult to attain. Researchers found the scripts used to introduce the study to proxies to be long and inflexible, making it difficult to get past the initial wariness to deliver the intended message. Additionally, perhaps more importantly, the proxy may not perceive it to be in his or her best interest to relocate the resident.

3. Barriers to Referral

- a. Lack of Participating Agencies/Agency Limitations. Locating agencies to conduct needs assessment and determine viability of transition was made difficult by the current method used to segregate the different programs and populations served. In this study it was particularly difficult for the residents under age 65. On several occasions there was simply no place to refer the resident.
- b. Misinterpretation of Policy. Related to the above, some agencies interpreted DHCS or program policy incorrectly, which lead to delays in assessment. For example, in one instance an agency believed incorrectly that a Medi-Cal beneficiary with a share of cost was not eligible for the ALWPP, and therefore refused to accept the referral

- and conduct an assessment. It was later determined that this interpretation was not correct. In the ALWPP the beneficiary is financially responsible for room and board.
- c. System Barriers. The multiple HCBS waiver system itself is a barrier. Conflicting objectives and criteria lead to confusion all across the system as to who conducts assessments for and access to each HCBS waiver.

4. Barriers to Relocation

- a. Resident Reluctance. Proxy reluctance to relocate residents was discussed above. Sometimes, however, it is the resident who is reluctant to move. While it was not prevalent in the population studied during phase II, (only five self-consenting residents refused to be interviewed, and only nine expressed a preference *not* to move), this can occur for a number of reasons. The resident may be afraid they won't get the care they need, or be unfamiliar with available resources and may not perceive his or her situation to be conducive to living anywhere other than a nursing facility. Additionally, some residents may be entirely content with their living arrangements. They find the convenience of having all needed services in the facility to be a true convenience. Based on the results of this study, these appear to be a very small minority.
- b. Level of need. Sometimes the needs of the resident are too great, and relocating from the nursing facility is not feasible, even if the preference exists.
- c. Financial constraints. Limited resources are common in this population and may lead to barriers for relocating. While assistance is available to provide for needed services, enough income to cover room and board payments (since room and board payments do not "follow the person") may not be available. A shortage of adequate and/or affordable housing is also a significant barrier, particularly in expensive Los Angeles County. In addition, relocation may require funds for security and utility deposits. Residents may simply have no monies available to cover these costs.
- d. System Barriers. These barriers relate to specific policies established to support the current system, or particular needs of the system rather than the needs of the client. An example would be the different criteria for Medi-Cal eligibility requirements for nursing home services versus for receiving home and community based services (e.g., through IHSS), and the apparent difficulty in changing Medi-Cal eligibility status and service setting. In addition, as mentioned above, the waiver system itself is a barrier. Also, certain operational policies may be a barrier, such as the requirement for the resident to be out of the nursing home *prior to* approving ramps or other home improvements. This requirement impacted the relocation of two individuals during the study.

Chapter 8
Recommendations

Recommendation 1: Directly measure preferences of long stay NF residents:

The preference protocol used in this project should be used with NF residents who are in the long-term stay portion of the facility since the MDS has not been accurate in identifying people who believe it feasible to relocate.

The JAGS article clearly shows that less demented residents who are listed in the MDS and the medical record as able to make their own health care decisions are most likely to believe it is feasible to relocate. This group can be accurately identified with MDS data available to DHCS and should receive first priority for assessment. It should be noted that this project did not target people in the facility for rehabilitation and it is possible that the MDS is more accurate identifying people who want to relocate in this population.

Recommendation 2: Target potential candidates early after post-acute stay

Our data indicate that length of stay in the facility is a key determinant in whether or not a resident successfully transitions out of the facility. The longer an individual resides in the facility, the less likely it is that he will transition back to the community. Identifying those residents with a preference to return to the community earlier rather than later, and taking steps toward that end, will improve success. Procedures to address this should be built into the program even if the resident may not actually relocate earlier than 6 months based on established federal protocol requirements.

Recommendation 3: Implement consistent methodology to identify self-consenters

Financial responsibility is not an adequate indicator of whether an individual is a reliable source of information, nor is the financial decision-maker necessarily the same person as the authorized health care proxy decision-maker. The MDS Recall Sub-scale is a standardized test that reliably predicts a resident's ability to accurately state a preference, and should be used in lieu of financial responsibility recorded on the face sheet.

The MDS Recall assessment requires residents to answer four orientation questions: The current season, location of own room, staff names and/or faces, and awareness of being in a nursing home. The resident receives one point for each correct response. Residents who score 2 or more points are considered capable of accurately stating their preference. Residents with a score of 0 or 1 cannot be relied upon to respond accurately to the interview questions. For these residents a proxy should be contacted.

Recommendation 4: Determine service needs within an integrated system (Stage 2 Assessment)

The assessment grid in Chapter 2 shows that most tools assess similar constructs (e.g., functioning, diseases/conditions, medications, treatments), but vary in their level of detail and the mechanism by which information is collected. The diversity in assessment tools is apparent in

the purpose and usage of each tool. Some tools address a narrow purpose, for example, facilitating nursing facility transitions (i.e., Santa Rosa, Texas) or determining eligibility for a waiver program (i.e., ALWPP, MI-Choice). Other tools are employed within the context of a specific program (e.g., MSSP, IHSS). In either case, however, these limited-use tools can create duplication and fragmentation within a system and often subject individuals to multiple assessments to obtain needed services.

We recommend an alternative: adoption of a uniform assessment tool employed within the context of an integrated system. Ideally, this tool should apply to more than one population and to multiple programs within the state of California. Through the use of this tool, an individual would have a single entry into a system of needed programs and services. For best results, the assessment information should be gathered electronically using a single tool and translated into care plans and reimbursement levels via standardized algorithms. Assessment findings could be used to determine eligibility and provide older adults and disabled persons with access to a range of programs and services. Assessment information would be housed in a single database to reduce duplicative data collection and to facilitate information sharing across programs.

Key characteristics:

- Uniform assessment tool
- Electronic data entry
- Integrated information system
- Algorithms to link assessment findings to care planning and reimbursement levels

Of the instruments we reviewed, three meet the above criteria: those used in Washington, Oregon, and Wisconsin. Of these three, we recommend that policymakers closely examine the Washington CARE tool, because it has been administered extensively throughout the state and is used within an integrated system. Furthermore, Washington has evaluated the tool's inter-rater reliability and empirically tested its algorithms, which are used to predict resource allocation. Finally, contacts in Washington have willingly shared their experiences with the tool and have even offered technical assistance. Although the programming costs of developing a similar instrument for use in California are unknown, the Washington tool can be modified to suit California's needs, which include both nursing facility diversion and transition. Limitations of adopting the Washington tool include the tool's modification costs; the costs of using or modifying the software associated with the Washington system; lack of published studies on the tool's reliability or how well the assessment has worked in reducing NF placement; and the fact that social workers or licensed nurses might have to administer the assessment, as they currently do in Washington. It should be noted that this last limitation also applies to most of the other assessment tools reviewed here; to date, no studies have examined the qualifications or educational level needed to administer any of the assessments.

In California, the San Mateo County Division of Aging and Adult Services is developing a uniform assessment tool that will integrate multiple programs, including IHSS, APS, MSSP,

Linkages, and AIDS case management. The tool is based on the MDS-HC, but has been tailored to incorporate specific requirements for the MSSP and AIDS programs. We recommend that policymakers examine the San Mateo tool because it has integrated requirements of specific California programs (i.e., MSSP and IHSS) and therefore may be adaptable for statewide use as well as use in nursing facility diversion and transition programs. An advantage of the MDS-HC is that it can be licensed from the Inter-RAI organization at no cost to the state. However, the length of the licensing process is unknown, and the license permits users to add, subtract, or change only 5% of the assessment items. Furthermore, the MDS-HC has been psychometrically tested for reliability. Nevertheless, the San Mateo tool is worth carefully considering as it develops. Whatever assessment protocol is utilized; clear instructions about how the data is to be collected should be developed. Community agencies appear to use different data sources to assess a resident's suitability for relocation (either proxies or resident self reports), which creates different conclusions about service needs. The preferable assessment method would be to conduct independent performance assessments of the resident's capabilities when possible.

Recommendation 5: Incentives for community agencies and nursing homes

The incentives that community agencies have to work with more difficult relocation candidates and particularly candidates with housing problems should be reviewed. These residents clearly are more labor intense to relocate than people who are in the hospital or NF for rehabilitation. Agencies may make decisions not to move forward on these cases due to the absence of incentives to do so. Similarly, facilities do not have a strong incentive to participate in this project and policies should be developed at the state level to assure access to all Medi-Cal residents.

Recommendation 6: Screen self-consenters first

In light of the time and expense of interviewing residents with proxy representation, screening self-consenters first is an efficient way to target individuals, especially after implementing a more adequate methodology of identifying who the self-consenters are.

Recommendation 7: Ensure proxy education early in the process.

Nursing facilities could be incentivised to provide information to family members about the availability of services to help care for loved ones in the community. The ability to identify the benefits to the families or caregivers is critical to successful transition. This may help set expectations early on, even if, or especially if, the resident is self-consenting upon admission.

Recommendation 8: Ensure the Transition Coordinator Role is Defined and Implemented

The Transition Coordinator plays a key role in the success of the process. The Transition Coordinator provides case-level experience that is required to identify and address issues and barriers in the system, and to navigate multiple programs. The Transition Coordinator is accountable for managing coordination and communication between the client, family, nursing facility and the agency, which takes a great deal of effort. Each case brings with it different combinations of issues and the solutions to these problems don't necessarily fit into a mould.

The Transition Coordinator has the objectivity to ask, “What will best serve clients’ needs?” This should be the most important question to consider.

Recommendation 9: Design operational policies to meet the needs of the people served

To meet the needs of this vulnerable group, policies should be more person-centered and easier for the individual rather than supporting outdated systems. Form should follow function, which means that policy design should be predicated on its intent or purpose. If the intent is to help someone, ensure that procedures are flexible and support that end. Prepare care plans and handle discharge planning to deliver services in a way that all persons who may be candidates for relocating get what they need when they need it. If a resident needs several hundred dollars to cover a security deposit, a clear-cut and timely process that is understood by all must be in place to ensure the funds are provided. Likewise, if a person needs a wheelchair ramp installed in the home so that he/she can safely come and go, there must be adequate procedures to get this ramp installed prior to discharge from the nursing facility. Only then will there exist a process where the money truly follows the person.

Recommendation 10: Ensure availability of bi-lingual staff

Although historically nursing home residents tended to be Caucasian, there is a shift happening and an increasing number of residents are from different ethnic backgrounds. It is recommended that this be considered both during the assessment process as well as when transitioning residents and arranging for services.

Chapter 9
Conclusion

The California Pathways study objectives of developing a comprehensive assessment protocol to facilitate relocation decisions and piloting an intervention to relocate nursing residents to the community were met. The assessment instrument developed performed as intended, and successfully identified preference to transition to the community. The intervention protocol was also tested, however its success is not as apparent since few residents transitioned under it.

The study identified several barriers that, if removed, will improve the smooth functioning of the protocol. Several recommendations were outlined that may help to remove some of these barriers. The current system is structurally, fiscally and programmatically fragmented. To reduce system barriers as well as duplication of effort, programs should not be artificially separated by age, specified diagnoses or functional limitations. Rather, programs should focus on designing processes to determine the in-home services needed, and how to deliver these services in the most effective manner.

Other states such as Washington, Oregon and Vermont are developing comprehensive, integrated delivery systems in which money is able to follow the person across service settings. These have met with reasonably good success in rebalancing their long-term care systems. Although none of these states is as large or as complex as California, they nevertheless offer innovations that should be considered both in terms of their overall approach and their specific components or tools that they use to build their systems. Major structural change of the type implemented in these states, is recommended in order for California to develop a system where money follows the person and consumer preference dictates setting of care.