

# **Aged Care Innovative Pool dementia and disability pilot services evaluation**

**Report on the scope of a national evaluation  
framework**

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## Summary

This paper summarises a project undertaken by the Ageing and Aged Care Unit at the Australian Institute of Health and Welfare (AIHW) to define the scope of work for the development of a national evaluation framework for the Aged Care Innovative Pool dementia care and disability services. The main objectives of the study were to

1. determine whether one framework could be designed to cover evaluation requirements in the dementia and disability streams of Innovative Pool;
2. define the broad scope of outcome measurement;
3. identify issues to be considered in the specification of objectives for the national evaluation; and
4. outline a scope of work for the evaluation projects.

The AIHW proposes that one set of core outcome and activity measures can be adopted to evaluate the dementia care and disability services pilot programs. This paper makes recommendations on the broad scope of an evaluation framework, focussing specifically on outcome measures and measurement instruments that could be used to generate data for a suite of evaluation data sets in each stream. Multiple outcome measures will be necessary to increase the validity of the evaluation, promote qualitative understanding of evaluation results and generate results that can be compared to national program and survey data. A combination of health outcome and utilisation outcome measures will ensure that relevant short and long term outcomes are considered.

### Core health outcome measures

Outcome measures that cover the functioning and disability components (body, activity and participation) and contextual factors (to do with the person and his or her environment) of the International Classification of Functioning, Disability and Health (ICF) are the conceptual ideal for evaluating disability-related needs and how those needs are met by innovative care services. Community care for a person with a disability focuses on the activity and participation aspects of daily living and involves a holistic assessment of the person in his or her social environment. A review of the literature identified three domains, activity, participation, and social resources, as critical areas of outcome measurement in an evaluation of the impact of community-based dementia and disability services.

In selecting specific outcome measures and measurement instruments in each of the key domains a number of other factors need to be taken into account. The single group treatment design implemented ahead of the program evaluation design means that some compromise is necessary to generate data that could potentially be used to compare client profiles and outcomes to those of the wider population with a disability and age-related needs. Validity and test/retest reliability, desirable

psychometric properties in any measurement of health outcomes, become paramount in a research design for which equivalent comparison groups might not be universally available and where the period of evaluation places a greater reliance on intermediate outcome measures. The phasing in of pilot sites over a period of over 12 months is a further practical consideration. Some providers have been delivering services to clients for many months while others are still in the set-up phase. It was therefore desirable to define a scope of outcome measurement that can be readily incorporated into established and widespread client assessment procedures.

A set of health outcome measures and instruments for use in the Innovative Pool evaluations is listed below. These cover the domains of client functioning and behaviour (where appropriate), self- or reliable informant-rated health status and participation in life areas, and carer well-being. It is not suggested that the recommended instruments are necessarily the best available tools, rather that they represent a compromise in the present context. For comparative purposes, scores from the Home and Community Care (HACC) functional screening instrument should be collected. Service providers in most jurisdictions have been collecting this data for some time, either as a local requirement, or in preparation for inclusion in the HACC minimum data set from July 2005. Because the instrument has not been subjected to rigorous validity and reliability testing, it is recommended that two additional items from the underlying instrumental activities of daily living (IADL) scale<sup>1</sup> be collected. There is research evidence that these two items are important predictors of hours of paid and unpaid help in their own right (LaPlante, Harrington & Kang 2002). Their inclusion will ensure that the evaluation has access to scores that are generated by a valid and reliable IADL instrument without a major duplication of effort for service providers and clients.

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<sup>1</sup> Older American Resources and Services multidimensional functional assessment questionnaire (Fillenbaum 1988).

## Core health outcome measures proposed for the Innovative Pool evaluations

Domain	Instrument	Scope	Required scores
Client ADL	20-point Modified Barthel Index (Collins scoring)	All clients at entry, discharge and interim assessment points	10 item scores
Client IADL	HACC functional screening instrument <sup>(a)</sup> plus items on meal preparation and telephone use from the OARS MFAQ IADL scale	All clients at entry, discharge and interim assessment points	<ul style="list-style-type: none"> <li>• Scores for items 1–7 on the HACC instrument<sup>(a)</sup></li> <li>• Scores for meal preparation and telephone use items on the OARS MFAQ scale.</li> </ul>
Client behaviour	1. HACC functional screening instrument behaviour items  2. Adapted Resident Classification Scale behaviour sub-scale. A scale for carer subjective response rating is added to each item in the adapted scale.	All clients on entry  Measure on entry, discharge and interim assessment points for <ul style="list-style-type: none"> <li>• Clients in dementia care high care need or challenging behaviour pilots.</li> <li>• Other clients for whom a behaviour assessment is triggered by the HACC screening items.</li> </ul>	Scores for items 8 and 9  Scores for RCS items 9–14 and carer response score for each item if applicable.
Client cognitive functioning	Mini-Mental State Examination	All clients on entry and discharge	Total score
Carer burden	Carer Strain Index	All primary carers on entry, discharge and interim assessment points	Total score
Carer psychological well-being	General Health Questionnaire (28 item version)	All primary on entry, discharge and interim assessment points	4 sub-scale scores
Self- or observer-rated health status	As per OARS MFAQ physical health scale item or similar Likert scale	All clients on entry and discharge  All primary carers on entry and discharge	One rating eg. Excellent...poor
Extent of participation	National Community Services Data Dictionary V3 data item <i>Participation extent</i>	All clients on entry and discharge	Ratings for participation areas 1 to 9 (Table 7)
Satisfaction with participation	National Community Services Data Dictionary V3 data item <i>Participation satisfaction level</i>	All clients on entry and discharge	Ratings for participation areas 1 to 9 (Table 7)

(a) The HACC functional screening instrument contains ADL, IADL and items on behaviour and cognition. All 9 items should be collected to facilitate comparisons that may be possible with program data. The 5 true IADL measures which originate from the OARS MFAQ IADL scale, together with 2 further items on telephone use and meal preparation will facilitate an evaluation of client IADL outcomes using an instrument that has been tested for reliability and validity.

The AIHW recognises that instruments need to be easy and economical to administer, while still providing the necessary amount and type of information for comprehensive evaluation. Depending on data availability and quality, it might be possible to implement a quasi-experimental research design to evaluation outcomes at individual sites. However, measurement instruments for core outcomes were selected on the basis that the only available data for a comparative evaluation would be historical program data.

The framework should also provide for the collection of data elements to provide context to the evaluation of health outcomes. A broad scope of such data is presented in sections 3.2 (client profile), 3.3 (client health status) and 3.4 (client social resources). Several of these data items will facilitate a comparison of clients in Innovative Pool programs with recipients of national aged care and disability services. For example, 'Client activity and participation – support needs' evaluation data elements are sourced from the Commonwealth-State/Territory Disability Agreement data dictionary definition for 'Activity and Participation – support needs' (AIHW 2002a). Similarly, 'Client core activity – level of difficulty' evaluation data items correspond to definitions from the International Classification of Functioning, Disability and Health (AIHW 2003b) and match 'Activity – level of difficulty' data elements defined in the Community Services and Aged Care Assessment Program data dictionaries (AIHW 2000; AIHW 2002b). If collected, these data items will generate data comparable with national program data and results from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers.

It is intended that the range of measures presented here, along with recommended measurement instruments, could form the basis of advice to service providers ahead of the full framework specification to remove uncertainty about evaluation requirements. Standardisation is recommended in order to maximise the potential for service model and client group comparisons. Other assessments and data items collected locally may be used to supplement the core measures. The framework itself will need to specify the details of client assessment for evaluation purposes. Optimally, core health measures will be recorded at entry to the pilot service and at approximate 60-day intervals during the evaluation period, with the last measurement on discharge (see section 2.6).

### **Utilisation outcome measures**

The proposed core utilisation outcome measures are listed below. The primary utilisation outcome measures are use of residential aged care services and hospital services. Evaluation of these outcomes depends upon the extent to which a quasi-experimental design can be implemented at least at a local level. For flow-through dementia care pilot programs (time-limited post-acute care services), the AIHW recommends that the evaluation framework allow for an analysis of rates of hospitalisation at the client level. This would require the collection of 12-month history of hospitalisation of clients prior to their entry into pilot programs.



## Utilisation outcome measures proposed for the Innovative Pool evaluations

Domain	Measure	Details
Discharge support arrangements	Living arrangement on discharge. Government-funded support programs on discharge.	Data definitions from the National Community Services and ACAP data dictionaries
Emergency department presentations	Number	
Planned hospitalisations	Number/LOS (admission & separation dates)	Principal diagnosis and AR-DRG (or surgical/medical indicator)
Unplanned hospitalisations	Number/LOS (admission & separation dates)	Principal diagnosis and AR-DRG (or surgical/medical indicator)
Potentially avoidable hospitalisations <sup>(a)</sup>	Number/LOS (admission & separation dates)	Principal diagnosis and AR-DRG (or surgical/medical indicator)

(a) Potentially avoidable hospitalisations are hospitalisations for ambulatory care sensitive conditions (see section 2.6 and Table 6). A second category will be hospitalisations within 28 days of an index admission that are for conditions related to the index admission.

Direct measurement of residential aged care outcomes will require a longer timeframe than the 2004 evaluation period. Ideally, the framework can provide for an evaluation of the impact of innovative care services on factors that are identified in the literature as contributing to the risk of premature or inappropriate entry to residential aged care and secondly, for longer-term follow-up of client living arrangements and length of stay in pilot programs. An *ex post* quasi-experimental design to evaluate the impact on longer-term utilisation outcomes would involve constructing equivalent comparison groups. Generating comparable point-in-time measures should be distinguished from the type of impact evaluation that facilitates attribution of client outcomes to interventions. Some possibilities for impact evaluation have been identified but further consultation is required. At this stage it is only necessary for the national evaluation framework to be sufficiently flexible for impact evaluation at sites where suitable data can be obtained, while retaining an overall action research focus.

### Recommended service type categories

Service providers will be asked to record client and carer service events against a standard set of service types listed below. Standard units of consumption for each service type are strongly recommended.

### Service type categories for recording client service events:

Service category	Units	Notes
<b>Case management</b>		
Initial in-home assessment	Hours	2 (One individual has been assigned to coordinate needs assessment and services for this client)
Follow-up assessment and service coordination	Number of contacts	1 (A case manager has been assigned to coordinated needs assessment and services for this client but more than one person will act in this capacity)  0 (No case manager has been assigned to this client)
Medication assessment reviews	Number of reviews	
<b>Medical and allied health services</b>		
General practitioner consultation (EPC)	Number of contacts	
General practitioner consultation (no EPC)	Number of contacts	
Nursing care	Number of contacts	
Physiotherapy	Sessions <sup>(a)</sup>	
Social work	Sessions <sup>(a)</sup>	
Occupational/diversional therapy	Sessions <sup>(a)</sup>	
Podiatry	Sessions <sup>(a)</sup>	
Dietician	Number of referrals	
Psychologist consultation	Sessions <sup>(a)</sup>	
Alternative therapies	Sessions <sup>(a)</sup>	
<b>Medical and allied health services continued</b>		
Other allied health service	Sessions <sup>(a)</sup>	Please specify
Geriatrician (including psychogeriatrician)	Number of contacts	
Neurologist	Number of contacts	
Psychiatrist	Number of contacts	
Other medical specialist	Number of contacts	Please specify
<b>Dementia (or memory)-specific health services</b>		
Dementia management service (including memory clinics)	Number of contacts	
Behaviour management service	Number of contacts	
Dementia advisory service including hotline (staff only)	Number of contacts	

(continued)

**Service type categories for recording client service events (continued):**

<b>Service category</b>	<b>Units</b>	<b>Notes</b>
<b>Community health services</b>		
Community mental health service	Number of contacts	
Memory clinic	Number of contacts	
Rehabilitation clinic	Number of contacts	
<b>In-home assistance</b>		
Personal care services	Sessions <sup>(a)</sup>	
Domestic assistance	Sessions <sup>(a)</sup>	
Delivered meals	Number of meals	
Meal preparation/ food services (other than delivered meals)	Sessions <sup>(a)</sup>	
Linen services	Number of deliveries	
Transport services	Number of one-way trips	
Home maintenance (excluding home modifications)	Dollars	
Social support	Sessions <sup>(a)</sup>	
<b>Other community services</b>		
Employment referral & counselling	Number of contacts	
Day leisure/recreational program	Days	
Financial planning/management	Number of contacts	
Interpreter/translator	Dollars	
Temporary accommodation	Dollars	
Other accommodation assistance services	Dollars	
Other, please specify		
<b>Aids and equipment</b>		
Mobility aids	Dollars	
Vision aids	Dollars	
Hearing aids	Dollars	
Continence aids	Dollars	
Home modifications	Dollars	
Other, please specify		
<b>Carer respite services</b>		
In-home respite	Hours	
Day centre respite	Days	
Residential respite	Days	

*(continued)*

**Service type categories for recording client service events (continued):**

<b>Service category</b>	<b>Units</b>	<b>Notes</b>
<b>Other services for carers</b>		
Information and education services	Number of contacts	
Individual counselling and referral services (counselling for client should be recorded as social work)	Number of contacts	
Carer social support networks (focus groups, carer networks etc)	Number of events	Detail of type of service will be recorded against service provider
Dementia advisory service	Number of contacts	
Medical services through pilot program	Number of contacts	
Other, please specify		

Client service events for certain non-pilot services should also be included in the evaluation framework. Emergency department admissions and admitted patient services are required for reporting core utilisation outcome measures, but information on the use of other types of non-pilot services will also be required to inform recommendations for possible future program design. A list of proposed non-pilot services for inclusion in the framework is shown below.

**Non-pilot client service categories:**

<b>Service category</b>	<b>Unit</b>	<b>Notes</b>
<b>Hospital services (admitted patient care)</b>		
Day hospital (other than for psychogeriatric or psychiatric care)	Number of admissions	
Psychiatric unit	Number of admissions, LOS	
Psychogeriatric care unit	Number of contacts	
Overnight hospitalisation	Number of admissions, LOS (dates)	Principal diagnosis, urgency of admission, medical or surgical
Emergency department presentation	Number and dates	
<b>Medical services (outpatient)</b>		
General practitioner	Contacts	
Medical specialist	Contacts	

(a) Standard sessions of 15 minutes duration.

Part 3 of this report presents a broad scope of data items to be collected on clients, carers and service providers at baseline in addition to the core outcome and activity measures listed above. The national evaluation framework should specify data definitions for these data items in accordance with the latest available versions of the National Community Services Data Dictionary, National Health Data Dictionary, the Aged Care Assessment Program Data Dictionary and the Commonwealth-

State/Territory Disability Agreement Data Dictionary. These documents are available on the AIHW web site ([www.aihw.gov.au](http://www.aihw.gov.au)).

# **1 Introduction**

## **1.1 Project brief**

This report presents the findings of a project to define the scope of work for the evaluation of pilot services in the dementia and disability streams of the Aged Care Innovative Pool (IP). The Ageing and Aged Care Unit of the Australian Institute of Health and Welfare (AIHW) completed the project under a schedule of the Memorandum of Understanding between the Australian Government Department of Health and Ageing (the Department) and the AIHW. The study was an opportunity to research issues of measurement and evaluation to assist the AIHW in offering advice on data collection and the feasibility of a consistent approach to evaluation for dementia and disability pilots funded from the Innovative Pool. Information compiled during the study was used to sketch a project outline that will assist in planning the national evaluation project.

Within the disability stream, the Department has already received proposals for projects that are designed to address the needs of people who are ageing with a disability. The Innovative Pool guidelines also provide for proposals designed to address the needs of younger people in nursing homes. The Department and the AIHW agreed that the scoping study should consider only the former component of the disability stream because the two distinct types of pilot services are likely to differ to an extent that would preclude one evaluation framework doing justice to both.

## **1.2 Outline of the report**

Part 2 of this report is a review of research in the area of community care, approaches to health and social services research and issues specific to the evaluation of dementia and disability services. The review concludes with a discussion of client assessment and outcome measurement in health services research. Drawing on the findings of previous studies of the various factors that influence living arrangement outcomes for older people with dementia and disabilities and the literature on geriatric assessment more generally, the present study examined a range of assessment instruments for the measurement of health outcomes. In addition, national data definitions and some more widely used measures were assessed for their appropriateness in the evaluation framework. Part 2 summarises the findings of these investigations and highlights aspects that should be considered in the selection of outcome measures and assessment tools – the different stakeholder perspectives of health service outcomes, measurement timing, utilisation and functional outcomes, carer outcomes and measures of health status in older populations. Here, too, the complexities of health-related quality of life for older people is discussed.

The literature review lays the foundation for the selection of a set of core outcome measures and service types for activity and process measurement in the evaluation

framework (Part 3). A minimum set of outcome measures for the evaluations is presented in section 3.1. Sections 3.2–3.6 describe distinct sets of data items that could be used as the basis for evaluation data set specification. Using the scope of measurement outlined in Part 3 of the report, it is envisaged that the evaluation of each stream of services within the Innovative Pool will be able to draw on one set of core data elements. Part 3 also proposes a number of client assessment instruments for inclusion in the national evaluation framework.

Part 4 presents an evaluation project outline including time estimates and extensions to the basic evaluation that might be considered.

## 2 Literature review

### 2.1 Preamble

The design of the Aged Care Innovative Pool dementia and disability pilot programs exemplifies ‘action research’ – a way of generating knowledge about a social system while, at the same time, attempting to change it. Innovative care for older persons in the community would appear to fall into the category of ‘empowering’ action research. As described by Hart & Bond (1998), “the empowering type is most closely associated with community development approaches and is characterised by an explicit anti-oppressive stance to working with vulnerable groups in society”. Given the amorphous collection of single study group pilots that come under the Innovative Pool, a flexible and adaptable approach to evaluation will be required. Impact and outcome evaluation may need to take on different forms and be implemented at pilot-site level within each of the streams.

In broad terms, the objectives of impact and outcome evaluation (PHRN 2002) will be to:

1. assess the relationship between program activities and observed outcomes and quantify the costs associated with those activities and outcomes; and
2. gain insight into how programs should be designed and targeted to bring about desired outcomes in a cost-effective manner.

The ‘activities’ component involves profiling each pilot program according to service environment and the range of services offered to clients. The ‘outcomes’ component involves defining and collecting measures of health status, utilisation outcomes – including utilisation and cost of pilot program services; utilisation of institutional care, intermediate-result outcomes (for example, carer burden, client satisfaction) and end-result outcomes (for example change in functional status, change in extent of participation in life activities). An important question then, is how to make use of this information to assess the success or otherwise of pilot programs in achieving outcomes. Is it reasonable to define ‘success’ mainly in terms of utilisation outcomes? What do we know about the relationship between the different types of outcome measure listed above and how could we use this knowledge to define a framework for the evaluation of Innovative Pool pilot programs? What research design might overlay the single group treatment design?

This review of the literature begins by exploring evidence on the role of formal community-based services in helping at-risk older people to avoid premature or inappropriate entry to residential care facilities. Research in this area has examined how different types of community care – formal and informal – impact on the use of residential aged care facilities and acute care services. Much of our knowledge about risk factors for entry to permanent residential aged care comes from evaluations of community care programs and studies of the relationship between formal and informal care. Sloan et al. (1995) cite a number of studies that suggest that



community-based formal support does not contain total long-term care costs unless services are targeted precisely to those older persons most likely to be institutionalised. A 'continuum of care' model emerges as a plausible explanation for patterns of service utilisation that have been observed in research as well as national program data in Australia.

Secondly, we review published findings on the service needs and evaluation of services for older people with dementia and disability. We then raise a number of issues to do with measuring health outcomes, including a section on the intermediate outcome of carer burden as a risk factor for entry to permanent residential aged care. The review concludes with a broad scope for outcome measurement in the pilot evaluations, giving examples of standard measurement instruments and data definitions. Special considerations in relation to domains of measurement, or the use of instruments, are noted in this final part of the review.

## **2.2 A framework to describe the interaction between informal care and formal community-based services in the balance of care**

Informal care provided by family and friends is an important source of long-term care for frail older people and people of all ages with severe disability. Hence, policies for the provision of formal services in the community must take into account the crucial component of informal care. Despite a vast body of research on the subject, this relationship between informal care and the use of formal services is not well defined. Much of the research has focussed on whether formal services in the community can substitute for informal care rather than focusing on the integration of formal and informal care (Mauser & Miller 1994: 20).

In fact, three main hypotheses for the interaction between the role of informal and formal care in the community are to be found in the literature: substitution, buffering and supplementation. Andersen (1995) and Andersen and Newman (1973) developed a conceptual model for health service utilisation that helps to differentiate between these hypotheses. The model describes the use of health services as a function of factors operating on three levels: whole of society, health system, and individual. Factors operating at the individual level are further classified as need factors (for example level of disability, co-morbidity, functional capacity, general health status), predisposing factors (for example age, sex, education, ethnicity, occupation, attitudes and values) and enabling factors (family and social resources). The three hypotheses offer alternative explanations of how the predisposing, need and enabling factors operate at the individual level.

One hypothesis – substitution – proposes that informal care and formal community-based services are independent enabling factors. If they operate independently, informal care and formal services in the community can theoretically substitute for each other, and both are substitutes for certain forms of institutional care (discussed in Newman et al. 1990; Jette et al. 1995). It follows that the availability of informal care and formal community-based services could therefore independently lower an individual's risk of entry to permanent residential aged care.

This theory has arguably attracted the greatest amount of research interest and some authors have reported substitution effects (for example, Greene 1983; Cantor 1979). The evidence of formal services substituting for informal care to effectively reduce rates of entry to residential care facilities has, however, been qualified by definitions of 'level of informal care' and 'level of formal care'. The introduction of formal services in one or more care domains can bring about a reduction in the number of areas that is primarily serviced by informal carers without actually reducing the amount of informal care that is delivered across all areas. Expressing 'level of care' simply in terms of the number of service types without consideration for intensity, duration, or quality of the care provided can appear as substitution when in fact, specialisation or supplementation has taken place (Greene 1983). Moreover, interpretation of what constitutes 'substitution' is inconsistent. An investigation into predictors of in-home formal service use among older people in the United States revealed a higher probability of formal service use among those who lived alone. However, those who lived alone received fewer visits than people who did not live alone, other things being equal (Mauser & Miller 1994: 30).

No clear pattern of substitution between institutional care and home care has emerged from studies across the OECD:

*There is plenty of evidence that community care options can enable frail older people to stay in their own homes. However, whether it is cheaper and whether it reduces the use of alternatives is much more doubtful. In experimental situations where there is a coordinated effort and competent case management, some substitution effect can be found, but even in such cases the evidence is not overwhelming...A single demonstration in a single state cannot show us whether these conditions can be replicated and maintained in an ongoing program (Kemper et al. 1987) (OECD 1996: 74).*

Weissert and colleagues' 1988 review of home and community care in the United States concluded that community-based services "probably did reduce nursing home use in the majority of studies, but typically the level of use available to be reduced was small, the amount of reduction small, and so potential for cost reduction was relatively small" (cited in OECD 1996: 75). As early as 1992, an Australian evaluation reported that "the original concern with inappropriate admission to residential care is now dated because of improved assessment and admission procedures" (DHHCS 1992 cited in OECD 1996: 76). Segal (2002) has also questioned whether the expectation that 'low cost' community care can replace 'high cost' institutional care is well founded. Regardless, the international literature on home care as a substitute for institutional care continues to build as demand for health and social welfare services is expected to increase in rapidly ageing populations.

Newman et al. (1990) proposed a 'buffering' hypothesis to explain the relationship between community care and long-term living arrangement. Here, receipt of care in the community is thought to moderate the effects of other risk factors, such as functional limitation. Individuals in poor health who have access to higher levels of community services would thus be able to avoid premature or inappropriate entry to

residential care facilities at a higher rate than those unable to access services. This theory would be supported by observing a statistically significant interaction effect between severity of disability and the amount of formal and/or informal care in mitigating the risk of premature or inappropriate entry to residential care facilities. In terms of the Andersen model, the buffering hypothesis proposes that the use of both informal care and formal community-based services would be higher in individuals with higher levels of need.

A third conceptualisation, the supplementation hypothesis, suggests that formal services enhance the effectiveness of informal care in delaying or preventing long-term institutional care (Edelman & Hughes 1990). There would thus be an inverse association between the totality of care received and risk of entry to a residential aged care facility, but not necessarily between the separate components of care (formal versus informal) and long-term living arrangement. With supplementary roles, additional formal services do not necessarily reduce the level of informal care. Specialisation may be viewed as a form of supplementation, whereby formal and informal care providers have different domains of responsibility, with informal carers acting as a 'bridge' to formal services (Edelbrock et al. 2003). The supplementation hypothesis is consistent with informal care and formal services acting as joint enabling factors as defined by the Andersen model.

Research in Australia and elsewhere has delivered inconsistent verdicts on each of these theories. Empirical results have tended to reflect diverse research methods and study populations. A high quality cohort study with 6-year follow up conducted in the United States presents as a particularly cogent treatment of the research question (Jette et al. 1995). Longitudinal data on community-dwelling older people in Massachusetts were used to test all 3 hypotheses. The study found that the interaction between formal services and informal care in preventing premature or inappropriate entry to residential is highly contextual. Although differences in international conditions and currency limit the extent to which results of overseas research can be generalised, this work is particularly relevant to the current context because the policy environment at the time was echoed some 10 years later in Australia. Baseline for the study was 1984–85, 10 years after the introduction of a publicly funded statewide home care program. Public policy changes during the 1980s increased access to case-managed community-based care and established a gate-keeping procedure to manage access to long-term institutional care.

Regression analysis of a model formulated to test the substitution hypothesis produced predictable results for certain key enabling factors but did not lend unequivocal support to the substitution theory. Having a co-resident carer was found to significantly reduce the risk of entry to a long-term residential care facility, while having a male carer was found to significantly increase the risk. The analysis indicated that disabled older people with a male primary carer were at over twice the risk of admission to institutional care than subjects with a female primary carer. Significantly higher risk of admission to a nursing home was found to be associated

with older age (OR<sup>2</sup> 1.53; 95% CI<sup>3</sup> 1.3-1.9), more severe disability (OR 1.36; 95% CI 1.2-1.6), cognitive impairment (OR 2.6; 95% CI 1.6-4.1) and carer burden (OR 1.94; 95% CI 1.1-3.3). A higher level of formal care, measured in hours per week, was associated with higher rates of admission to a nursing home during the study period (OR 1.41; 95% CI 1.0-1.9), although this variable only just met the 5% level of significance (Jette et al. 1995: S9).

To test the buffering hypothesis, Jette and colleagues tested both the interaction between cognitive impairment and hours of informal and formal care, and the interaction between severity of physical disability and hours of informal and formal care. If formal and informal care do indeed buffer the risk of entry to permanent residential aged care that is associated with severe disability then, they hypothesised, the analysis would generate significant results for these interaction effects. However, only the interaction between cognitive impairment and hours of formal care reached statistical significance, and then, only just (OR 0.80; 95% CI 0.6-1.0). In other words, among individuals with cognitive impairment, those who received a greater number of hours of community-based formal care experienced a significantly lower risk of entry to a permanent residential aged care facility to those who received less formal care. There was no evidence of a similar buffering of physical disability by formal services. Nor was there any evidence of informal care having a buffering effect on either cognitive impairment or physical disability.

Analysis of the statistical model that was formulated to test the supplementation hypothesis produced an unexpected result. Older people who received both informal and formal care at home experienced over twice the risk of entry to permanent residential aged care than those who received informal care only (OR 2.57; 95% CI 1.3-5.0). One possible explanation put forward is that supplementation of informal care with formal community-based services represents a milestone in the care continuum for many older people with a severe level of disability. The authors characterised this continuum as beginning with mainly informal care, progressing to mixed informal and formal care and possibly finishing with full formal (institutional) care. Empirical support for this explanation has emerged from other studies. For example, Schneider et al. (2003) found evidence of supplementation in the early stages of care for people with dementia, followed by substitution as the person with dementia entered residential care and the Sydney Older Persons Study found that older people with high levels of informal care made greater use of medical services (Edelbrock et al. 2003).

Cross-sectional data on national aged care programs in Australia tend to support the care continuum theory of supplementation followed by substitution. Current trends also suggest that the timing of milestones in relation to functional ability might vary depending on the level of certain enabling factors for an individual. In 2000-01, Aged Care Assessment Team (ACAT) clients living at home alone at the time of assessment were more likely to be recommended for residential care (38.6%) than clients living

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<sup>2</sup> Odds ratio.

<sup>3</sup> Confidence interval

with other people (34.1%) or a spouse only (29.2%). However clients living at home alone were more likely to be recommended for low-level care than for high-level care (26.2% versus 12.4%) (LGC 2002: 55). These results have been interpreted as evidence that recommendations for low-level residential care are often based on the psychosocial needs of the client who lives alone as much as functional dependency and further, that living with others helps people to remain in the community until they require high-level care (LGC 2002: 55).

Patterns of service use among Community Aged Care Package (CACP) clients are consistent with these observations of ACAT recommendations (AIHW analysis of the 2002 CACP census data). The likelihood of a client having used any one type of service during the census period was surprisingly similar for the with-carer and without-carer client groups. The main difference to appear was that clients without a co-resident carer were more likely to use social support services, suggesting that formal social support services provide a substitute for the informal care network. Clients living with a carer appeared to be a more highly dependent group, registering approximately twice the rate of diagnosed dementia as clients without a carer. Moreover, a higher proportion of clients with a co-resident carer used personal care services. The fact that the presence of a co-resident carer was not associated with markedly lower average rates of formal service use provides some support for the supplementation hypothesis although the exact relationship between this pattern of supplementation and rates of entry to residential aged care services cannot be determined from cross-sectional census data. These patterns are consistent with the Aged Care Assessment Program results, but longitudinal data on aged care service delivery are required for a more definitive answer to these questions.

The Innovative Pool pilot programs provide an opportunity to evaluate the performance of different models of service provision in different populations with possibly different needs. The evaluation time frame, however, limits the extent to which a reliable conclusion can be made about substitution potential, other than by measuring intermediate outcomes (eg. observed impact of pilot program activities on factors known to be associated with entry to residential aged care facilities). A recommendation of the Massachusetts study provides a possible frame of reference for the evaluation of dementia and disability pilot services:

*Future hypothesis testing should move beyond global hypotheses regarding the protective effects of community-based support services and examine the specific risk factors for specific subgroups of older persons. Findings from this study suggest that those who continue to ask whether informal and formal community support services influence the risk of future nursing home use are pursuing the wrong question. The issue is what type of service – under what circumstance and for what type of older person – will influence subsequent risk of entering a nursing home. (Jette et al., 1995)*

Here, a key term is 'risk'. Being in need of assistance and demonstrating benefit from additional services is not the same as being 'at risk' of entry to permanent residential aged care (Davies 1993, 1994; Kemper et al. 1987 cited in OECD 1996: 75). Evaluation studies have tended to focus on short-term benefits that might not be evident given a long-term perspective. Nonetheless, there is broader potential benefit from improved targeting of available services. Better targeting, however, does not necessarily reduce

costs since it inevitably produces a more demanding caseload. An OECD report cites the example of hospital 'bedblockers' being used as a convenient excuse for keeping out patients who would require expensive medical treatment, even where hospitals and community services are funded from the same budget (OECD 1996: 75). Conversely, Fisher and Fine (2002) cite examples which showed that people at immediate risk of entry to a residential aged care facility did not benefit from the additional resources allocated to case management, whereas people with lower level needs did.

Given the difficulty that has been encountered in attempts to demonstrate short-term substitution effects, causal relationships and cost effectiveness, an alternative perspective of 'outcome' might be required. Poor physical health, past levels of service utilisation, recent significant health events such as falls and fractures, especially those involving hospitalisation, and carer burden are widely recognised risk factors for entry to a long-term residential aged care facility and formal service use in general (see for example DHS 2003; DVA 1993; Eagar, Green & Adamson 2002). Rather than focus exclusively on the outcomes of hospital readmission rates and admission to long-term residential care, an evaluation of time-limited health care interventions might make greater use of intermediate outcomes. Evidence of an improvement in intermediate outcomes that are known risk factors for penultimate outcomes is evidence of a desirable effect.

Short-term hospital admission and readmission rates can be calculated but are circumspect measures of longer-term rates. Post-acute care services deal with clients who have experienced a significant health event or collapse of social support. It might be impractical to base an evaluation on lower total rates of hospital readmission within a 3 to 6 month period (the question of 'avoidable' or 'preventable' hospitalisation is, however, important and is discussed in more detail below). A more realistic expectation might be shorter length of stay when hospitalisation is required. Perhaps only the longer-term readmission rate is a valid outcome measure of community support interventions. The national evaluation framework could emphasise the observed impact of innovative care services on known risk factors using both quantitative and qualitative research methods.

The principle of normalisation, concerned with the interests of people themselves, was central to the de-institutionalisation movement and continues to be an important principle of community care policy:

*Without a decent supply of home- and community-based services, and without opportunities for older people [and younger people with a disability] and their carers to participate in normal social life, ageing in place could well be associated with increasing neglect and isolation for too many people. If this is the case, life in an institution could well be a more attractive option, one which should not be dismissed too readily as long as other solutions have not been put in place. (OECD 1996: 77).*

A corollary for the evaluation of innovative care services, then, is that a holistic approach would consider the individual and carer, if applicable, in a social context: level of function, scope for social participation, perception of well-being and life satisfaction.

The continuum of care theory offers a useful model for the national evaluation framework for dementia and disability pilot services. Ideally, an assessment of where each client (and carer) is situated on the care continuum at entry to the pilot program could be made. It would be possible to do this consistent with current programs. The Aged Care Assessment Program data dictionary, for example, defines 'at-risk' ACAT clients as those who exhibit four or all of the five following characteristics (AIHW 2002b):

- aged 80 years or over (or 60 years or over for clients of Aboriginal and/or Torres Strait Islander origin);
- severe or profound core activity restriction;
- dementia;
- living alone;
- without a carer.

Past patterns of formal service use will be relevant here, but so too are judgements of participants and case managers. Subjective measures of carer predisposition towards their care recipient being admitted to formal long-term care, taken at time of entry to the pilot service and on discharge, might complement objective measures of client functional status and carer burden. It is clear from the literature that decisions surrounding entry to permanent residential aged care are rarely objective and are influenced by cultural expectations. Client and carer perceptions of the availability of ongoing support in the community are as relevant as objective measures and clinical observation of client functional independence.

### **2.3 Dementia: tipping the balance of care**

The projected increase in the cost of dementia care is a significant challenge for policy makers worldwide. Failing major pharmacological breakthroughs, the ageing population in Australia will see a rapid increase in the prevalence of dementia over the next few decades (Jorm & Henderson 1993). Growth in the number of cases of Alzheimer's disease, responsible for over 70% of dementia disorders, will be a major contributing factor (Ojeda et al. 1986 cited in Jorm & Henderson 1993). Clinically, 'dementia' refers to a behaviour syndrome defined by loss of intellectual capacity and social function (Bond & Corner 2001). Memory loss, reduced capacity for decision making and problem solving, unacceptable social behaviour and nocturnal activity all contribute to the labour intensity and distress that can be associated with caring for a person with dementia.

Stewart's (1998) economic perspective of Alzheimer's disease summarises some of the main points in the literature on dementia care and treatment.

- Morbidity associated with Alzheimer's disease leads to very high economic costs, direct and indirect, formal and informal.

- One of the most significant drivers of direct health and social services costs is the requirement for residential care, although the associated variation in indirect and informal costs is more complex.
- It is often assumed that costs are linked to levels of functioning and dependency, but a variety of other patient and carer characteristics are also significant.
- No drug interventions have yet been clearly demonstrated to show a significant economic benefit, in a robust manner.

In 1996, dementia of any type was the second leading cause of non-fatal disease burden for females and the fourth for males in Australia (AIHW 1999: 51). Projections based on prevalence rates recorded in the 1998 ABS Survey of Disability, Ageing and Carers estimate the number of persons with diagnosed dementia in 2002 at around 120,900 (78,700 females and 42,100 males). This number is projected to increase to around 190,700 by 2020<sup>4</sup>: 116,800 females and 73,900 males (AIHW 2003a). *Access Economics* (2003) has published a considerably higher estimate of 162,000 persons with dementia in 2002.

Dementia is the most common primary diagnosis made by aged care assessment teams in Australia (LGC 2002: 36). High rates of admission to permanent residential care are associated with dementia yet admission to a long-term care facility or hospital can have significant negative consequences for a person with dementia (Zarit et al. 1980; Lo Giudice et al. 1995). In 1998, an estimated 72% of persons who reported dementia had lived in cared accommodation for 3 months or more (AIHW 2003a). An unpublished AIHW analysis of data from the 1998 ABS Survey of Disability Ageing and Carers investigated the association between a diagnosis of dementia and living arrangement. Analysis was confined to survey data for people aged 65 years or more with a severe or profound core activity restriction (of any origin). Among people aged 65–74 years with a severe or profound restriction, the odds of residing in cared accommodation for a person with dementia was estimated to be 11 times the odds for a person without dementia (95% confidence interval 6.6–16.5). A separate analysis of data for people aged 85 or more years revealed that the odds of residing in cared accommodation for a person with dementia were approximately 6 times the odds for people without dementia (95% confidence interval 3.7–9.9).

LoGiudice and colleagues (1997) followed a cohort of older people who had been referred to a Victorian Aged Care Assessment Team over a 12-month period to measure the impact of cognitive impairment on direct and indirect costs of care in the community and accommodation outcome. Most of the clients who remained at home without an increase in services were cognitively normal. About half of the clients who remained at home with an increase in community services were cognitively impaired and most of these clients lived with a carer. Most of the clients who were living at home at the time of referral and who were subsequently admitted to residential care were cognitively impaired (half of these clients had lived alone at

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<sup>4</sup> AIHW projections are based on the number of persons reporting dementia in the 1998 ABS Survey of Disability, Ageing and Carers, and ABS population estimates for 30 June 2002 and 2020.



referral). Cognitive impairment was the most important determinant of entry to a long-term residential aged care facility within 12 months of referral for this group, with an estimated risk ratio of 9.9 (95% confidence interval 3.0–41.0).

Persons with dementia may require 24-hour supervision (Henderson & Jorm 1998). In addition to the projected increase in the prevalence of dementia, a rapid rise in the number of older people living alone, predominantly women, signals increasing demand for informal dementia care provided by the working-age population -- primarily daughters and daughters-in-law if current trends in informal care are to continue. The care burden of dementia has considerable implications for workforce participation and superannuation coverage as well as the widely acknowledged impacts on carer health and wellbeing and capacity for social participation.

#### *Predictors of entry to residential aged care facilities*

The symptoms of Alzheimer's disease change over the course of the disease and needs for assistance change accordingly. Investigators have reported variously on factors that are predictive of an older person entering long-term residential aged care. Colerick and George (1986) found that people with Alzheimer's disease who had been admitted to a nursing home were more likely than those remaining in the community to have had a younger, employed female primary carer. The authors emphasised that there may be underlying difficulties with attempts at a reductionist analysis in this area.

Mittelman et al. (1993) cited the findings of a number of studies:

- Knopman et al. (1988) and Steele et al. (1990) found that paranoia and agitation were predictors of entry to an aged care facility for long-term care, however the work of Colerick & George (1986) and Lieberman & Kramer (1991) suggested that behavioural disorders are not significant factors;
- Knopman et al. (1988) and Zarit et al. (1986) found that high need for assistance with instrumental activities of daily living is a precursor to entry to permanent residential care;
- O'Donnell et al. (1992) and Zarit et al. (1986) reported on the role of incontinence in leading to placement of the dementia patient in cared accommodation; and
- other factors including poor physical health (Greene & Ondirich, 1990), recent hospitalisation (Shapiro & Tate, 1988) and self-perception of poor health status (Cohen et al., 1986; Shapiro & Tate, 1988) have also been implicated.

Mittelman et al. (1993) evaluated a carer intervention designed to delay the entry to long-term care facilities of people with dementia who had a spouse primary carer. Multivariate analysis of data from the randomised controlled study revealed significantly higher odds of entry to long-term formal residential care among subjects with a high need for assistance in activities of daily living (ADL), and this was almost entirely explained by the incontinence indicator. It was proposed that following the onset of incontinence, the carer is unable to "maintain the myth" that the person with dementia is their former self, or indeed, a normal adult. With this realisation there may be a growing perception that there is less to justify the effort required for maintaining the person at home. The carer intervention itself was associated with a

significantly lower rate of entry to a residential care facility after adjusting for age (patient and carer), carer sex, income, patient ADL and carer burden.

Henderson and Jorm (1998: 54) cite Morris and colleagues who remarked that “institutionalisation may have more to do with the attitudes and well-being of the caregiver than the impairment of the dementia sufferer”. Some researchers have reported on the higher resilience of spouse carers in assisting their care recipients to avoid entry to a residential aged care facility (Colerick & George, 1986; Shapiro & Tate, 1988; Mittelman et al., 1993). Others have found no significant difference in outcomes for people with spouse carers and those with other types of coresident carers, suggesting that coresidency, not relationship, is the primary risk modifier (Tennstedt et al. 1993; Jette et al., 1995). Phillips and Diwan (2003) reported that the presence of a team of informal carers was associated with earlier nursing home placement of people with dementia. Whether team support indicates higher client needs and/or primary carer burden, or a lower level of support than would be provided by a single primary carer, is open to conjecture. Survival analysis undertaken in this study revealed a significant relationship between dementia-related problem behaviours and time to nursing home placement among older people with dementia living in the community.

To summarise, research suggests that the circumstances surrounding admission to cared accommodation are complex and personal. They include aspects of the social, economic and physical environment of the person with dementia as much as cognitive and functional status. Investigations of entry to a residential aged care facility would ideally consider the physical and cognitive state of the person with dementia and level of function in activities of daily living and instrumental activities of daily living. They would also take into account aspects of the social environment – current availability of home care, wider social support for the patient and carer, and the prospects for longer-term informal care in the community.

#### *Cost relativities of institutional and community-based dementia care*

Gray and Fenn’s (1993) comparative study of some common diseases of old age found dementia care in the United Kingdom to be more costly than care for other conditions such as stroke. The costs of institutional care account for a large proportion of dementia care expenditure. Currently, direct health costs of dementia in Australia are estimated at around \$3.2 billion per annum, of which \$2.9 billion is spent on residential care (Access Economics 2003).

That it is less costly to maintain an older person with dementia in the community largely reflects the undervalued labour component of the informal care sector. Kendig et al. (cited in LoGiudice et al. 1997) reported that in Australia, the costs of community care increase with dependency level, dementia severity and lack of a coresident carer. Research in the United States has shown labour time of the primary carer to be the single most important component of the cost of home care. The United States National Advisory Council on Aging estimated the equivalent per annum costs for community-dwelling and institutionalised older persons with dementia in 1995. For those in the community the majority of care costs were attributable to the imputed value of unpaid informal care (cited in Moore et al. 2001). This latter

amount is not inconsiderable and highlights the importance of providing assistance to support family carers. In Australia, informal care for people with dementia has been valued at a replacement cost of \$1.7 billion in 2002 (Access Economics 2003).

The previously mentioned Australian study by Lo Giudice et al. found that average monthly per person government or agency costs for non-residential services were 31% higher for the cognitively impaired group relative to average cost for the cognitively normal group, while average out-of-pocket expenses in the two groups were comparable. The cognitively impaired group incurred considerably higher government/agency and out-of-pocket expenses for residential services (\$2,103.00 plus \$350.00 on average per month in 1997) than the cognitively normal group (\$1,243.50 plus \$71.50 on average per month in 1997). Acute and specialist geriatric (hospital) care was included in the costs of residential services and was a large component of the cost of residential services in both groups, accounting for 48% and 65% of total government costs for the cognitively impaired and cognitively normal groups respectively. Indirect costs to carers were found to not differ significantly between the two groups, although the analysis did not include the replacement value of foregone income, which did not appear to be a major issue for this particular group of carers.

This study confirmed the findings of international research: that it is less costly to maintain an older person with dementia at home than to provide care in a residential setting when the replacement value of informal care is excluded. Psychological morbidity among home carers was high and did not differ significantly between carers with cognitively normal and cognitively impaired spouses at baseline. The group caring for a person with dementia experienced a significant increase in psychological morbidity and carer burden over the study period while, on average, psychological morbidity decreased among carers with cognitively normal spouses. LoGiudice et al. (1997) concluded that

*There seems to be a large gap in the ability to service adequately the needs of those with dementia living at home, so that residential care becomes the only option...It may be possible to target a subgroup of this population that may benefit from innovative home care schemes in an attempt to avoid institutionalisation. It is imperative, however, that alternative options do not subsequently place extra financial or social costs on carers.*

High levels of dependency associated with severe cognitive impairment have been found to impose additional costs in the order of 25%, holding other patient and location factors constant (Kavanagh et al. 1993). Dependency is associated not only with the dementia itself, but with high levels of co-morbid disease in older persons generally. Demand and supply side factors can be identified in the transition from home to institutional care (Warburton 1994). Demand side factors reflect the characteristics of older population groups, the link between age and admissions, and also a link with health problems that have generated a prior admission to hospital (Stewart 1998). Many older people move directly from hospital to residential care, or are at least assessed for eligibility while in hospital. Dementia-related demand for

residential care has been linked to the stress on carers supporting people with dementia at home. An unrelated acute episode or the onset of rapid functional decline due to the dementia itself that leads to a hospital is likely to be associated with increased dependency, and heightened carer burden (increased cost of informal care). Hospitalisation, therefore, can represent a significant event in the care continuum, signalling a change in demand side factors.

Cognitively impaired hospitalised patients are less stable and experience increased morbidity and mortality. They are at higher risk of loss of independence, post-operative complications and behavioural difficulties than cognitively normal hospitalised age cohorts (Gallo et al. 2000: 30). These changes in demand side factors may be reversible but the immediacy brought about by pressure on public hospital beds carries the risk of premature or inappropriate entry to a residential aged care facility. Alternative responses such as providing increased support for a willing informal carer have considerably different long-term public welfare cost implications.

On the supply side, home-based assistance for clients and carers can ameliorate the impact of dementia on the balance of care. In the United Kingdom, it has been observed that persons with dementia of equal severity may receive differing levels of care because community-based services tend to target those living alone (Stewart 1998). Resource allocation decisions to support people with little chance of remaining in the community long-term because of living arrangement may be cost inefficient if, as a result, fewer services are available to those who have better prospects for long-term informal care.

#### *Rates of decline in late-onset Alzheimer's disease*

In a study aiming to measure patient outcomes in terms of functional status, it might be useful to have access to norms for rates of functional decline. Holmes and Lovestone (2003) published the following benchmarks in the context of evaluating the efficacy of pharmacological agents in the treatment of dementia symptoms. Measurements were taken from subjects who were not participating in drug trials nor using cholinesterase inhibitors. The Mini-Mental State Examination (MMSE) was used to measure cognitive status and a short-form Blessed Dementia Rating Scale (BDRS) was used for functional status. Rates of decline were reported for each year of a 3-year follow-up period. Three-year mean rates are presented here.

The mean rate of cognitive decline in a sample of older people with late-onset Alzheimer's disease was 2.2 (s.d. 3.4) MMSE points per year relative to a baseline mean of 9.9 (s.d. 7.1) points. Considering only cases of mild or moderate dementia at baseline, the mean rate of cognitive decline was 3.4 (s.d. 3.5) MMSE points per year relative to a baseline means score of 17.0 (s.d. 3.5) points.

The mean rate of functional decline was 1.3 (s.d. 2.2) BDRS points per year for all cases relative to a baseline mean of 8.8 (s.d. 4.0) points. For cases of mild or moderate dementia at baseline, the mean rate of functional decline was 1.2 (s.d. 2.6) BDRS points. Baseline mean BDRS score for mild to moderate cases was not reported.

In the first year of follow-up, 39.0% of survivors showed an improvement or no change on the MMSE and 44% of survivors showed an improvement or no change on the BDRS. In the third year, these proportions were 24.7% (MMSE) and 15.5% (BDRS). Difficulties in benchmarking cognitive and functional decline in Alzheimer's disease arise from wide variation between subjects, inter- and intra-rater variability and known non-linearity in cognitive assessment tools. It is suggested that rate of cognitive and functional change cannot be reliably used as a simple indicator of treatment response (Holmes & Lovestone 2003).

## **2.4 Disability and ageing**

According to the ABS Survey of Disability, Ageing and Carers, 316,800 people aged 65 or more years who had a severe or profound core activity restriction were living in private dwellings in 1998, including 97,900 people who were living alone (ABS 1999). Approximately 15% of older people living in households who had a disability reported a need for assistance with personal activities (Table 1). Assistance was more likely to be required for mobility and health care (13% and 18% respectively of older people with a disability). Among those who reported a need for assistance with self-care – eating, bathing, dressing, grooming and toilet use – 14% said that their needs were not fully met by current sources of formal and informal assistance. For mobility, the corresponding proportion was 19%.

Reasons for unsatisfied demand include individuals' reluctance to seek assistance, problems in accessing adequate informal care from family and friends, and issues of access and cost of formal services. Within the older population with a disability are individuals who experience severe or profound restriction in performing core daily activities. Unsatisfied demand for assistance with core activities in this group presents a risk of avoidable entry to residential care facilities. The Innovative Pool evaluations therefore present as a timely assessment of services designed to assist older people whose needs might not be addressed by current service types.

**Table 1: Persons aged 65 years or more living in households, need for assistance by activity type and extent to which demand for assistance was satisfied, Australia, 1998**

	Fully satisfied	Partially satisfied	Total	Proportion of all older persons
	'000	'000	'000	Per cent
<b>Activities for which assistance needed</b>				
Personal activities <sup>(a)</sup>				
Self-care	133.3	21.7	155.0	7.4
Mobility	223.8	51.1	275.0	13.1
Communication	24.4	*3.1	28.3	1.3
Health care	320.1	55.9	376.0	17.9
<i>All needing assistance with personal activities</i>	<i>249.0</i>	<i>69.6</i>	<i>318.6</i>	<i>15.1</i>
Transport	366.0	87.9	453.9	21.6
Paperwork	131.4	12.9	144.3	6.9
Housework	335.9	68.0	403.9	19.2
Property maintenance	485.5	140.6	626.1	29.8
Meal preparation	131.1	11.1	142.2	6.8
<b>Total needing assistance with at least one activity</b>	<b>594.6</b>	<b>293.2</b>	<b>887.9</b>	<b>42.2</b>

(a) These activities were only asked of persons with a disability.

\* Subject to a relative standard error of 25–50%.

Source: ABS 1999: Table 24.

People with early-onset disability often experience age-related needs at an earlier age than would otherwise be the case and age-related needs may differ depending on whether a person has an intellectual or physical disability. Table 2 summarises 1998 ABS survey data on the need for assistance with personal activities (self-care, mobility, communication and health care) among people aged 45 years or more with a severe or profound core activity restriction, by age of disability onset. Firstly, we note that the absolute numbers of people aged 45–64 years who reported a need for assistance in each area were similar to the numbers in the older population at the time. Presently, there is a one-off effect of the ‘baby boom’ generation following on the heels of the older cohort that is itself ageing due to increasing average life expectancy. Of the people who had a severe or profound core activity restriction and whose disability dated back to youth, over 50% reported a need for assistance with self-care and health care, and over 80% needed assistance with mobility. In fact, a higher proportion of people with very early onset disability needed assistance with mobility in their middle to old age than did people whose disability surfaced later in life.

Many people with early onset disability face specific challenges relating to accommodation and social support in their middle to later years due to the emergence of age-related needs. The next topic examines specific issues relating to Commonwealth-State/Territory Disability Agreement clients who are ageing.

**Table 2: People aged 45 years and over with a severe or profound core activity restriction living in households: need for assistance in performing core activities of daily living<sup>(a)</sup> and health care, by age at onset of main condition, Australia, 1998<sup>(b)</sup>**

	Current age 45–64 years				Current age 65 years or over				
	Age at onset of main condition				Age at onset of main condition				
	0–17	18–44	45–64	Total	0–17	18–44	45–64	65+	Total
<b>Self-care</b>									
Need ('000)	16.0	80.6	62.6	159.2	*3.7	21.1	51.8	75.7	152.4
Do not need ('000)	14.1	52.6	48.1	114.8	9.3	27.8	41.6	88.6	167.3
% needing help	53.2	60.5	56.5	58.1	*28.6	43.2	55.5	46.1	47.7
<b>Mobility</b>									
Need ('000)	24.5	98.5	85.7	208.7	12.3	43.7	72.8	140.2	269.0
Do not need ('000)	*5.7	34.7	25.0	65.3	**0.7	*5.3	20.6	23.8	50.3
% needing help	81.2	74.0	77.4	76.2	94.6	89.2	78.0	85.5	84.2
<b>Communication</b>									
Need ('000)	*3.4	*3.4	**2.2	*9.0	**0.6	*2.7	*6.2	18.5	28.0
Do not need ('000)	26.8	129.7	108.5	265.1	12.4	46.3	87.1	145.5	291.4
% needing help	*11.2	*2.6	**2.0	*3.3	**4.4	*5.5	*6.7	11.3	8.8
<b>Health care</b>									
Need ('000)	16.9	67.4	59.9	144.2	10.1	32.9	61.0	107.7	211.8
Do not need ('000)	13.3	65.8	50.8	129.8	*2.9	16.0	32.3	56.3	107.5
% needing help	56.0	50.6	54.1	52.6	77.5	67.2	65.4	65.7	66.3

(a) Self-care, mobility and communication.

(b) Estimates marked with \*\* have an associated relative standard error (RSE) of 50% or more. Estimates marked with \* have an associated RSE of between 25% and 50%. These estimates should be interpreted accordingly.

Source: AIHW 2000a: Table 15.14.

### *Implications of ageing for CSTDA clients*

Following the widespread adoption of deinstitutionalisation policy and practice, the concept of normalisation for people with a disability tends to shift focus from an issue of 'rights' to a 'prescription' for services in general, and residential patterns in particular (Brown et al. 1989). While residential arrangements will vary considerably for older people with disabilities, ranging from family home to community group home to more institutional settings, Brown and colleagues have suggested a number of common goals and criteria:

- increasing traditional curriculum areas;
- participation in the community and at home;
- participation in household management;
- reducing behaviours that interfere with participation; and
- increasing enjoyment of life at home and in the community.

Choice and satisfaction are of paramount importance to people with disabilities, their carers and service providers (AIHW 2002c). In this context, satisfaction refers to whether the level of participation experienced is personally fulfilling and appropriate. People with early-onset disabilities are vulnerable to the effects of limited incomes and social support on their capacity to make life choices. Many people with a lifelong disability may lose the opportunity for sheltered work and day recreational programs oriented for younger people as they age. In-home day care can provide an appropriate level of care but often only if there is support from informal carers. An Australian Housing and Urban Research Institute report suggests that those with the least access to informal care and suitable accommodation are more likely to be placed into cared accommodation even if that is not the preferred option:

*The trend towards 'ageing in place' recognises community care as being the preferred care context for older adults with disabilities, highlighting the inappropriateness of much of existing Australian infrastructure for people with disabilities, particularly housing and transport. It has also highlighted age specific program policies as barriers, particularly those concerning employment and day care (Bridge et al. 2002: ix).*

Other research has indicated that considerable unsatisfied demand exists because community care services for this group are fragmented and uncoordinated (cited in Bridge et al. 2002:viii). An AIHW report on unmet demand in disability services, undertaken at the request of the National Disability Administrators, has highlighted the mounting pressure on disability service programs to meet the needs of older people who are eligible under the Commonwealth-State/Territory Disability Agreement (AIHW 2002c: xxiii). Projected increases in the number of people with a severe or profound restriction aged 45 years or over mean that disability services will be attending to an increasingly older client population. Survival to older ages is now more frequent among people with an early onset disability and functional decline and diseases more typically associated with old age occur at an earlier age in people with early onset disability (Janicki et al. 1985; Gething & Fethney 1998; Suttie 1995; Bigby 1998; Cooper 1997). Intellectual, physical and psychiatric disabilities are the most common main disabilities among persons aged 45–59 years who received services under the Commonwealth-State/Territory Disability Agreements (CSTDA) in 2002 (85% of CSTDA consumers in this age group). Among CSTDA consumers aged 60 and over in 2002, intellectual, physical and vision impairments were the top 3 disability groups (Table 3).

Older people with intellectual disabilities are a heterogeneous group with an increased risk of other health problems such as sensory impairments, physical disabilities and epilepsy and they differ from their younger counterparts due to differential mortality rates (Holland & Moss cited in Thornicroft 2001). Studies have highlighted needs in the areas of social and recreational activity and community living skills as having priority over assistance with activities of daily living for many in this group (Gow & Chow cited in Thornicroft 2001).



**Table 3: Consumers of CSTDA-funded services aged 45 years and over on a snapshot day, primary disability group by age, 2002**

Primary disability group	Age group (years)		Total 45+
	45–59	60+	
Intellectual	7,959	1,752	9,711
Physical	1,663	701	2,364
Psychiatric	1,340	283	1,623
Acquired brain injury	707	220	927
Neurological disorder	627	289	916
Vision	234	888	1,122
Hearing	111	151	262
Other	133	33	166
Not stated	34	12	46
<b>Total</b>	<b>12,808</b>	<b>4,329</b>	<b>17,137</b>

Source: AIHW 2003c: Table 3.4

Between 1996 and 1999, age-specific growth in the number of recipients of CSTDA-funded services peaked at ages 45–49 years (total growth 42.2%; 11.7% average annual growth) to 55–59 years (57.6% total growth; 15.2% average annual growth) (AIHW 2000a: Table 17.7). High growth in the number of persons with severe or profound restriction at these ages creates additional demands on disability services to support an increasingly older client population and incentives to more carefully consider the interface between disability and aged care services.

Additional services made available through unmet needs funding have been well received however, reports of the strain faced by ageing long-term carers of people with a disability persist. According to an AIHW study team, “some carers are looking over the fence at the aged care system and believe there are more choices and options for people (both clients and carers) in that system” (AIHW 2002c: xix). The same study estimated remaining unsatisfied demand for CSTDA-specific services in 2001 as including a minimum of 12,500 people needing assistance at least 3–5 times per day with one ADL<sup>5</sup> or less frequent assistance with multiple ADL who were unable to access the required accommodation support and carer respite services. This was in addition to unsatisfied demand for community access and employment services (AIHW 2002c: xxi).

What provision or access gaps for people with a disability who are ageing have been identified? The answer to this question might provide insight into the types of services offered by pilot initiatives that will operate at the interface of disability and aged care services. The Functioning and Disability Unit at the AIHW completed a project on disability and ageing, which included a literature review and discussions

<sup>5</sup> Activities of daily living.

with peak bodies. Relevant sections of the project report are reproduced below, with due acknowledgment to the authors who work in the Functioning and Disability Unit. A bibliography for references in this section can be found in the full project report (AIHW 2000a).

*General issues concerning the need for appropriate services* (extract from AIHW 2000a: 49-51)

A large number of reports and special studies have indicated that the existing Australian service models and boundaries between different programs cannot accommodate the emerging needs of people with a disability who are ageing. In Australia, disability and age-related service organisations currently appear to be providing services to two distinct populations with little crossover or linkage (Buys & Rushworth 1997). Older adults with early onset disability are falling between disability services and generic aged care services but quite 'young' and/or unsuitable by the aged care services that focus on the needs of the frail aged (Bigby 1998).

Functional abilities, not age, should be the factor in determining the suitability of services and supports, according to Williams (1999). It is important to develop effective collaboration and cooperation between services within the disability service system and between the disability system and aged care and other generic service systems to meet the needs of older people with an early onset disability. However, the complexities surrounding service provision, particularly in relation to the interface between the aged care system and the disability services system, have resulted in difficulties in service planning and provision (e.g. Gatter 1996; Williams & Chad 1998; Bigby 1999).

It appears to be widely agreed that one of the principal goals of a service program for ageing people with a disability is to maintain people in the community accommodation option of their choice for as long as possible and to minimise premature admission to nursing homes (eg. Gatter 1996; Williams & Chad 1998).

It has been suggested that, where appropriate, generic services should be seen as the first option for older people with an early onset disability, especially for people with moderate or mild intellectual disability (Bigby 1992). This option is to meet the needs common to ageing people generally, corresponding to their biological, psychological and social ageing. Nevertheless, specialist services may be necessary to assist people in accessing generic services, or to ensure that generic services are provided in a sensitive and appropriate manner.

Since older people with an early onset disability are not a homogeneous group, service provision must be flexible to meet individual needs and circumstances and to accommodate individual differences in life experience, the ageing process, independent skill levels, health status, and particular interests and choices (Bigby 1992).

The existing problems of meeting the emerging needs of ageing clients with a disability are, to a large extent, related to the structures of service programs and the models of service delivery in use. For example, some ageing clients may not necessarily need new or additional services, but rather changes in the method of

service delivery. People ageing with an early onset disability may need the same services but at an earlier age than the general ageing population. Day services may need to be restructured from full-day to part-day activities, or day activity arrangements should be more flexible to provide opportunities for socialisation (e.g. Janicki et al. 1985; Gatter 1996; Ruggi 1998).

Even though some service agencies have been providing services to older adults with intellectual disabilities living in the community, further information is needed to assess whether these services are appropriate and adequate to meet the needs of those people (Buys & Rushworth 1997).

In developing services that meet the needs of older people with an early onset disability it is necessary to consider:

- the decreased functional abilities and increased frailty of the target population.
- decline in the development and retention of skills.
- reduced appropriateness of some components of existing services suitable for younger people with disabilities (e.g. Janicki et al. 1985; Bigby 1992).

The New South Wales Ageing and Disability Department and Health Department have jointly developed the Community Care Assessment Framework (response from New South Wales Ageing and Disability Department 1999). This framework assists in establishing a collaborative inter-agency process for comprehensive assessment of people who need complex, multiple or high levels of support. The framework applies a client-based approach, taking into account a person's overall needs. This new initiative has the potential to assist in resolving the issues arising for older people with an early onset disability whose needs cannot be met due to current program boundaries.

There is evidence that the number of workers with disabilities approaching retirement is growing. The issues surrounding the transition from work to retirement for people with a disability are being examined in a study commissioned by the Commonwealth government (Department of Family and Community Services 1999). The study examines both mainstream and specialist options for retirement support services and identifies client needs and best practice models. The study particularly considers:

- Who makes the retirement decision?
- If there is a tool to evaluate retirement suitability, how is it to be used and by whom?
- What are the best mainstream and specialist service options?
- Commonwealth and State government boundary difficulties (Williams 1999).

There are particular issues related to the interface between services for older people with a psychiatric disability and aged care services. A scoping study on older people and mental health explored possibilities for further improvement of health care services to meet the needs of older Australians with mental disorders and their carers (AIHW 1998; AIHW 1999). A report on the second stage of the study concluded that it is very difficult to obtain data on the target group from current national data

collections. Therefore, it is difficult to draw conclusions about the adequacy and appropriateness of services for older people with mental health problems. However, the report identified the national hospital morbidity database and Aged Care Assessment Program data as the most promising potential sources of data to gain information about service target groups (AIHW 1999).

Caring is a matter of mutuality and partnership between governments, community and informal carers (McDonald 1997). Currently there is an absence of clear policy regarding the intersection of formal and informal support systems, so that decisions and rules become ad hoc, local and inconsistent, and often results from informal negotiations between older people and formal and informal providers of support (McDonald 1997).

*Service gaps and needs for service responses in key areas* (extract from AIHW 2000a: 51-56)

A survey was conducted among 162 community-based organisations that assist older adults or people with intellectual disability in Brisbane, Queensland, regarding the types of programs offered to older adults with intellectual disability. The results showed that only 36% of the organisations had provided assistance to at least one older adult with intellectual disability in the past 12 months. Agencies assisting people with disabilities were more likely to have provided services to this group than organisations assisting the general older population. None of the agencies surveyed reported that they provided specialised programs or services to older adults with intellectual disabilities (Buys & Rushworth 1997).

Because of the relatively low numbers and wide dispersal of older people with an early onset disability living in the community, it may not generally be feasible to establish separate programs just for this client group. However, separate programs may be viable and necessary where and when concentrations of older people occur (Bigby 1992). It may be necessary to 'cluster' groups of older clients with early onset disability (ideally based on similarities of need) in order to achieve economies of scale (Ruggi 1998).

Studies that report on service structures and patterns of service use and provision in the United States may provide lessons and insights for Australia. One such study reported that there were three service sectors in Massachusetts that were used by older people with intellectual disability: an age-integrated mental retardation service sector, which caters mainly for younger adults and some older clients; an age-specialised sector for older people with mental retardation; and a generic ageing service sector (Seltzer 1998: 181).

Some Australian studies have compiled the strengths and weaknesses of these variations on disability services (AIHW 2000a: Table 9.1) and proposed that the Massachusetts service structure may be adapted as an integrated framework for service delivery to people with a disability who are ageing (Queensland Department of Family Services and Aboriginal and Islander Affairs 1994; Parsons 1993; Gatter 1996).

Some key service areas may require refinement to meet the emerging needs of people with a disability who are ageing:

- Accommodation support services

Many people ageing with a disability want to remain living at home, but the question is: will the support be there to enable them to do so? A study of the needs of members in the Paraplegic and Quadriplegic Association of New South Wales aged 50 and over showed that 60% of them reported that their support needs had changed over the last 5 years (Williams 1999). The report also found that respondents had great difficulty in identifying appropriate accommodation options with which they have no experience. Hence, 24% of respondents preferred nursing home accommodation simply because that was the one they were familiar with and which they thought would provide adequate support. The respondents also indicated that share housing accommodation was not a preferred option, though supported housing, where privacy was maintained, was seen as desirable (Williams 1999).

At present, group home residents with an early onset disability are expected to be away from their home during weekdays, either at work or at day or recreational programs. Current funding for group homes usually does not allow for a staff member to be on duty during the day. This will create an increasingly untenable situation in those homes which have an ageing resident (Gatter 1996).

The existing types of residential aged care facilities may not meet the needs of ageing people with an early onset disability who are younger and perhaps more physically able than most frail older people. Large congregate care arrangements are much less acceptable in the disability service sector than in the aged care sector.

The demand for accommodation support services by ageing parents for their adult sons and daughters with disabilities is expected to increase. Demand for respite services can also be expected to increase, especially from those families who have chosen to continue to care for their ageing relatives with a disability in the family home. The capacity of services to respond to more frequent crisis needs should be enhanced (Gatter 1996).

The use of flexible program times, part-time placements and 'phasing down' of attendance hours for day programs has a direct impact on the clients' accommodation situation. Older parents or family carers require respite from caring for their dependant adult with a disability (Ruggi 1998).

It was suggested that accommodation services may be supplemented by the provision of day activity and leisure programs either through assisting residential staff to develop a program or facilitating direct provision by specialist services (Bigby 1992).

- Day activity and leisure service programs

Programs for older people should have a reduced emphasis on formal vocational training and skill acquisition and more emphasis on retention of skills and the constructive use of leisure. Although various day and leisure activities exist for older people in the community, few programs offer the structure, supervision or continuity

required by many people with an early onset of disability. The main areas that should be developed or emphasised to improve day activity programs for this target group are summarised as:

- Flexible arrangement;
- Individualised planning for participants;
- Recognition of the need for skill maintenance and development; social interaction, fostering or maintaining informal support and advocacy networks;
- Skill development of staff in service networks; and
- The development of a policy framework for disability services that recognises and incorporates the above principles (e.g. Bigby 1992; Ruggi 1998).

### *Summary*

Innovative Pool pilot programs for people who are ageing with a disability will be designed to address age-related needs that may not be ideally provided for under clients' current living arrangements. These will include age-related decline in functional independence, loss of autonomy, and social support needs that commonly arise at older ages. Difficulties in the measurement of qualitative outcomes for people with intellectual disability are likely to be encountered, just as for participants in the dementia pilot programs. Proxy reports on levels of social participation may suffice in these circumstances. Quality of life measurement or assessment of participation for people with a physical disability is recommended for inclusion in the national evaluation framework. Family involvement in case management and counselling and access to appropriate respite services will be important aspects of process evaluation. Carer outcomes and carer satisfaction with pilot disability services should be part of the evaluation framework for disability services.

## **2.5 Research design for a national evaluation framework**

In his 1971 address to the American Psychological Association, Professor of Psychology and renowned specialist in program evaluation methodology, Donald T. Campbell, remarked,

“While all nations are engaged in trying out innovative reforms, none is yet organised to adequately evaluate the outcomes of its innovations” (cited in Saxe & Fine 1981).

Thirty years on, we are perhaps closer to Campbell's vision of an “experimenting society”, yet the constraints that are faced by contemporary program evaluation methodologists are as real today as they were back then. Campbell himself acknowledged the barriers to, and limitations of, blinded randomised designs for the purposes of socio-political research: “when a social experiment is testing proposed governmental policy it should be characterised by openness, honesty, accountability, equalitarianism and voluntarism ... the voting booth rather than the experimental

animal laboratory becomes the appropriate ethical model" (cited in Saxe & Fine 1981).

What are some of the assumptions of pure experimental design that may not be supported or supportable in social research context? The gold standard randomised controlled trial assumes that

- treatments are homogeneous and delivered under equal conditions; and
- there is a clear definition of outcomes at the outset that are expressed as one or more hypotheses about specific biomedical markers; and
- responses or behaviours that are evident in a controlled environment are also valid in the uncontrolled environment.

Controlling for all, or even most, of the exogenous factors through design and analysis is rarely possible in health services research. Moreover, the traditional experiment, whereby outcomes are grounded in the researchers' definition of the situation – the "dominant positivist paradigm" (Bond & Corner 2001) – may lead to the measurement of outcomes that are meaningless for the group under study. This is particularly the case in the evaluation of health outcomes for older people and people with complex care needs in general (see for example DHAC 2001; Segal 2002).

One randomised trial to assess the effectiveness of integrated care and case management underscores the qualifications that are inevitable even under the most ideal conditions for this type of evaluation. In a community where older people were already receiving home health services in an uncoordinated service environment, clients were randomly allocated to either a control group to receive usual care or an intervention group for care planning and coordinated service delivery (Bernabei et al. 1998). This study was able to demonstrate significant improvements in functional outcomes, use and costs of health services by following an experimental method. However, it was necessary to qualify the results because the study could not conform to the rigid criteria of a clinical trial. All professionals involved were aware of the assignment of patients to the control and intervention groups and as a consequence of informed consent, patients were also aware of the project and their group assignment. Patients and professionals remained blind to the assessment outcomes throughout the study, however case managers performed the assessments and were aware of group assignment.

It is rare to find this type of naturally occurring control and often problematic to construct one *post hoc*. Ethical reasons precluded the use of randomised controls in the design of Innovative Pool pilot programs. The eligibility requirement of an Aged Care Assessment Team recommendation for low- or high-level residential care means that each client admitted to a pilot program is, by definition, at risk of entry to permanent residential aged care due to a unique set of health and social circumstances. The best 'control' then, would appear to be the client's own history of functioning and service use. An implication of the single study group design is that an *ex post* quasi-experimental design or generic controls will be required if an impact evaluation is to be undertaken (see Rossi & Freeman 1993 for a discussion of

evaluation designs for partial coverage programs). The construction of external comparison groups for evaluation purposes will need to be sensitive to the eligibility criteria and service environments in order to avoid selection bias. Waiting lists are one means of establishing a valid control group when there are strict eligibility criteria and appropriate 'usual care' is available. But the complexity of client disability and disease profiles makes a true case control method limited in practicality.

There is growing recognition that the present type of evaluation calls for an approach that is different to the true experimental design and that this should be articulated in evaluation objectives. Social science research involves observation, questioning and interpretation, and refinement of knowledge in the light of observation – the study of people in their natural environment. Addressing priorities, challenges and the researcher perspective in research on aged care at the 2003 National Symposium on Ageing Research, Professors Hal Kendig (Dean, Faculty of Health Sciences, University of Sydney) and John Braithwaite (Law Program, Research School of Social Sciences, Australian National University) advocated a bio-psychosocial approach. Citing a compelling example from the field of criminal justice, Braithwaite contended that the "observation of practice" model of social sciences research has led to dramatic improvements in professional practice (see also Hart & Bond 1995). This model comprises:

1. Observation.
2. Theorise on apparently effective practice.
3. Refinement of practice in the light of theory.
4. Implementation and evaluation of refined practice.
5. Dissemination of findings linked to outcomes of interest to policy makers.

The rationale is that once we understand motivations and behaviour (steps 1 and 2), we can develop more sophisticated interventions (step 3). It puts the research question into the context of the complex social world rather than isolating the two by creating an artificial controlled environment. Braithwaite contends that this approach is appropriate for the "street level bureaucracies" of health and welfare. The reluctance to impose *a priori* theoretical frameworks implies an insistence that the social world must be discovered through observation (Bryman 1988 cited in Bond & Corner 2001). Hence, observation of practice research becomes a precursor, rather than a replacement, for the randomised controlled trial.

The outcomes of primary interest to policy makers in the evaluation of Innovative Pool pilot programs relate to patterns of use of residential aged care. The outcomes of primary interest to clients, their families and service providers will be those surrounding functional ability, access to timely support and satisfaction with care. Although related, there is marked temporal distance in measurement terms. Discussions between the AIHW and the Department have raised the time-limited nature of the pilot program evaluation and how this might impact on the validity of utilisation outcome measures. This paper summarises some of the literature on predictors of entry to long-term residential aged care to describe a complex interplay



of health and social factors in influencing the long-term care outcomes for older people with a disability. An understanding of the relationship between known risk factors and outcomes provides a basis for determining the scope of outcome measurement.

It will be important for the evaluation framework to allow flexibility for the assessment of intermediate outcomes and consideration of the unique circumstances of individual clients. The evaluation can pose questions to which answers are not forthcoming in the published literature. For example, less appears to be known about triggers in the care continuum for older people with a disability who do not have a primary carer. Empirical findings in Australia suggest that social support is more often the main reason for aged care assessment of people living alone than it is for people who live with others. Uncertainty still surrounds differences in experience and outcomes for people who live alone yet have access to a carer, or network of carers versus those who live alone with lower levels of informal care, or none at all. More research is needed on the service needs and preferences of people with an early onset physical or intellectual disability and people from culturally and linguistically diverse backgrounds and their carers. What are the specific risk factors for these groups? What level and type of services appear to modify those risk factors to overcome obstacles to living in the community? At what cost?

The 'observation of practice' model seems an appropriate overall approach to evaluation given the design of the Innovative Pool pilot programs. The evaluation framework might express the outcome of primary interest, reduction in rates of premature or inappropriate entry to residential aged care facilities, in terms of known risk factors. This alters the more conventional question of 'does this intervention reduce the rate of premature or inappropriate entry to residential aged care facilities?' to 'does this intervention reduce risk factor x, and in so doing show potential for delaying or preventing entry over the longer term?'. It can also aim to explore the unknown factors for specific population groups because the 'observation of practice' model does not impose *a priori* hypotheses about cause and effect.

Where suitable external data sources are identified, an *ex post* quasi-experimental evaluation could be performed on data at the local level. However this would necessarily require a staged evaluation for the longer-term measurement of utilisation outcomes. A more detailed discussion of measurement that covers some of these issues follows.

## 2.6 Outcome measurement

Multidimensional assessment sets geriatrics apart from other fields of medicine (Gallo 2000: 4). Functional status is just one aspect of 'health' and for older persons in particular, the quality and density of the social environment are critical factors in maintenance of independent living at home (Gallo et al. 2000: 21). The notion of 'social health' offers another view, which complements the reporting of symptoms, illness and functional ability (Bowling 1997: 4). Social health is defined "in terms of social support systems that might intervene and modify the effect of the environment and life stress events on physical and mental health... Both objective and subjective

constructs are included in this definition” (Donald 1978 cited in Bowling 1997). Function may be better described by a composite of items including diagnosis, self-ratings of health, professional ratings of health and fulfilment of personal and social roles (Kane & Kane 1981: 31). This suggests that a multidimensional approach, which looks beyond the traditional medical model of disease and functioning, is needed for any comprehensive evaluation of health care interventions for the older person.

For an older person with a disability, social health can be conceptualised and measured in terms of the informal support that is available in the community that assists him or her to remain in the community. Assessment can be restricted to objective measures, or can be extended to include self- or informant-reports of perceived social health (discussed below). Availability and type of primary carer can be regarded as one item on a social resources scale. Carer burden is one important dimension of social resources.

This section discusses outcome measures and highlights practical difficulties that have been encountered in outcome measurement in similar studies. It presents a number of standard instruments that could be used for core outcome measurement. A framework proposed by Mauser and Miller (1995) offers a convenient conceptualisation for this discussion (Table 4).

**Table 4: Taxonomy of health outcome measures**

Type of measure	Purpose	Example
End-result outcome	A quantified change in patient condition that is the objective of the provision of care and is (potentially) due to the provision of care	Changes and non-changes in functional and cognitive abilities, symptoms, emotional conditions intrinsic to the patient. Change in social participation.
Intermediate-result outcome	A quantified non-physiological or non-functional outcome of care that is intrinsic to the patient, the patient’s family or carer, or their behaviour.	Patient satisfaction; change in level of carer burden. Change in perception of health status.
Utilisation outcome	A quantification of health services use (or non-use) that is potentially attributable to the care under consideration.	Indicators of admission to hospital or institutional long-term care.

Source: Adapted from Mauser & Miller (1995).

Mauser and Miller distinguish between quantitative measures of aspects of health at a point in time (eg. indicators of incontinence, scores on ADL scales) and quantitative measures of *change* in measures of function. In their framework, ‘outcome’ equates to change that is “potentially due to care”. Likewise, the Australian Health Ministers’ Advisory Council has defined ‘health outcome’ in terms of intervention, change and attribution: “a change in an individual, a group, or population, which is attributable to an intervention or series of intervention” (cited in NARI 2001: 2). Attribution is perhaps the most challenging aspect of evaluation in health services research.

End-result outcomes, as defined here, are measures of change in an aspect of health that is specifically targeted by the care that is delivered. From the perspective of clients and service providers, services are primarily aimed at client (and carer) health

and social needs. According to the proposed taxonomy, this category of outcome measures might cover change in physiology and function, performance in activities of daily living, and changed patterns of behaviour, depending on the care plan. Utilisation outcomes are a primary focus of evaluation for policy makers and funding bodies. Mauser and Miller consider utilisation outcome measures as a “surrogate” end-result outcome measures because, while they are not necessarily the primary focus of care providers, they are highly correlated with functional outcomes, and are themselves a primary focus for policy and program development. Change in broader measures such as overall health status and level of participation in domestic and social life were not explicitly classified by Mauser and Miller, but should perhaps be considered in the present context (we have added them to Table 4 for this reason).

How do key stakeholders – clients, providers, insurers and payers, and regulators – rate the importance of these different types of outcome measures? Kane et al. (1994) present the results of a 1991 United States survey that showed the divergent views of stakeholder groups with respect to 21 possible outcomes in home and community care. The results are summarised in Table 5 (results for consumer representatives, and professional providers are not presented here).

Most notably, clients rated process measures more highly than measures of functional and service utilisation outcomes. Groups uniformly rated highly physical safety and freedom from abuse. Service providers and insurers/payers placed greater emphasis on institutional care outcomes. Apart from clients, no group rated family knowledge at higher than an average 74%; this outcome was mostly rated between 50 and 60 per cent. While it may not be possible to generalise these results to other populations and periods in time with any degree of confidence, they demonstrate that differing views on outcomes in community-based care are held.

The National Ageing Research Institute undertook a study of outcome measurement in rehabilitation services in Victoria, Australia. Clinicians were asked to comment on client outcomes other than ADL functioning that they would be interested in measuring. The following domains were identified:

- Quality of life.
- Client (and carer) satisfaction and general well-being.
- Client confidence and self-esteem.
- Performance in occupational and social health, including community integration.
- Medication management.
- Cognition.
- Nutritional status.

**Table 5: Relative importance<sup>(a)</sup> of home care outcomes as perceived by multiple constituencies, in relation to low- and high-needs client groups**

Client group	Clients	Paraprofessional providers	Insurers/payers	Regulators
<b>Low care clients</b>	Freedom from abuse (98)	Freedom from abuse (91)	Affordability (93)	Client choice (96)
	Satisfaction with care (80)	Nursing home admission (90)	Physical safety (90)	Satisfaction with care (92)
	Death (79)	Death (88)	Nursing home admission (86)	Freedom from abuse (91)
	Compliance with regimen (78)	Satisfaction with care (88)	Physical functioning (83)	Physical functioning (81)
	Physical safety (75)	Hospitalisation (87)	Freedom from abuse (83)	Physical safety (78)
	Symptom control (75)	Admission to other congregate setting (86)	Hospitalisation (83)	
	Physical safety (75)	Morbidity (83)	Morbidity (80)	
<b>High care clients</b>	Satisfaction with care (88)	Freedom from abuse (93)	Freedom from abuse (97)	Physiological functioning (96)
	Client knowledge (84)	Physical safety (88)	Affordability (93)	Symptom control (94)
	Family knowledge (84)	Satisfaction with care (86)	Nursing home admission (89)	Physical functioning (92)
	Compliance with regimen (83)	Morbidity (85)	Compliance with regimen (88)	Morbidity (92)
	Physical functioning (81)	Hospitalisation (80)	Physical functioning (87)	Freedom from abuse (91)
	Morbidity (80)	Nursing home admission (78)	Physical safety (87)	Satisfaction with care (90)
	Cognitive functioning (79)	Physiological functioning (78)	Hospitalisation (87)	Client choice (87)
			Morbidity (82)	Client knowledge (86)
			Client knowledge (80)	Physical safety (81)
				Compliance with regimen (77)

(a) Importance score from 100 (most important) to 0 (least important) is shown in parentheses for outcomes that received a score of 75 or higher.

Source: Adapted from Kane et al. (1994), Tables 2 and 3

Quality of life outcomes were felt to be of limited use for clients with chronic conditions and many of the current quality of life measures were perceived to be too generic. While client satisfaction was identified as an important area of outcome measurement, questions were raised about the best time to administer a satisfaction questionnaire. An accurate and reliable operationalisation of client or patient satisfaction has, in fact, eluded many researchers (Cooper & Jenkins 1998). In addition, the general question of the best time to measure all types of outcomes in clients with deteriorating conditions was raised. Therapists remarked that the benefits of occupational therapy interventions in helping clients to reintegrate to

normal living are largely overlooked by current practice in outcome measurement (NARI 2001: 27–29).

### **Time frame for outcome measurement**

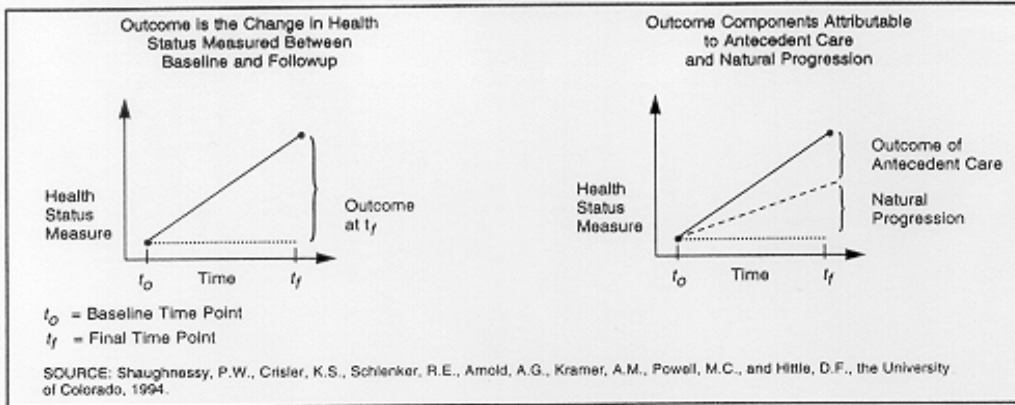
Conceptually, it is necessary to distinguish between an outcome and an outcome of care. Consider any of the end-result outcomes in Table 4 in the context of Figure 1. Some of the change that occurs between baseline time,  $t_0$ , and final time,  $t_f$ , will be independent of the care received because of natural progression in a person's health condition (including recovery from an acute episode of illness). This progression can be neutral, negative, or positive. Typically, control groups and statistical risk adjustment are used to make adjustments so that change in outcomes can be more reliably attributed to antecedent care. Shaughnessy et al. (1994) suggest that it is rarely possible to do this perfectly. This review has already alluded to the problems in applying principles of experimental design to health services research.

A second point to consider is the length of time between baseline and final outcome measurement. Figure 2 represents a scenario in which care between time  $t_0$  and an interim time,  $t_j$ , accelerated an improvement in health status. However, by the time of final outcome measurement,  $t_f$ , the impact of care is observed to be somewhat less than if final measurement had taken place at time  $t_j$ . Even a perfectly controlled trial cannot compensate for the unknown degree of influence of individual and environmental factors in the progression of disease and rates of recovery. Shaughnessy and colleagues noted, "no matter what final time point is selected to measure outcomes, the dilemma of the 'truly final effect' persists from a theoretical viewpoint". Other research has highlighted the non-linearity in health outcomes during rehabilitation (Carey et al. 1988).

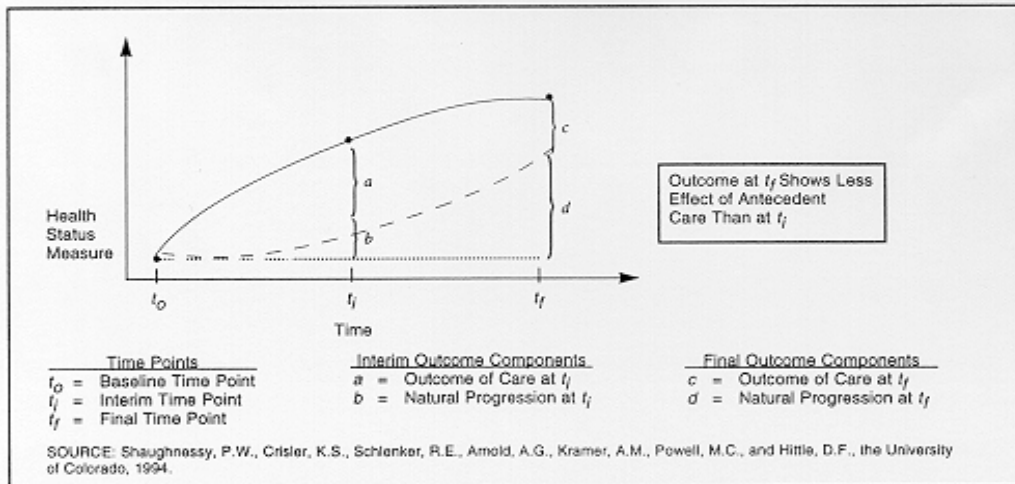
Thirdly, point-in-time measurement is susceptible to highlighting extreme points that occur in patients who experience erratic improvement over a period of time (Figure 3). For older people receiving health interventions in a community setting, Shaughnessy et al. (1994) have recommended outcome measurement every 60 days until discharge with the recording of final measures at discharge whenever it occurs. This suggestion is based on detailed analysis of patterns of change in functional outcomes using large longitudinal data sets. Although a more ideal measurement interval would be 30 days, this was thought to be impractical in most cases. The next multiple of 30 days is therefore a pragmatic compromise. Any longer and there is a greater risk of the confounding effects of other interventions and change in circumstances having too great an influence. Carey et al. (1988) have suggested that rehabilitation outcomes in post-acute older patients with low functional status on commencement tend to peak after about 6 weeks of therapy. Patients with higher functional status on commencement of therapy showed more benefit from longer periods of rehabilitation.



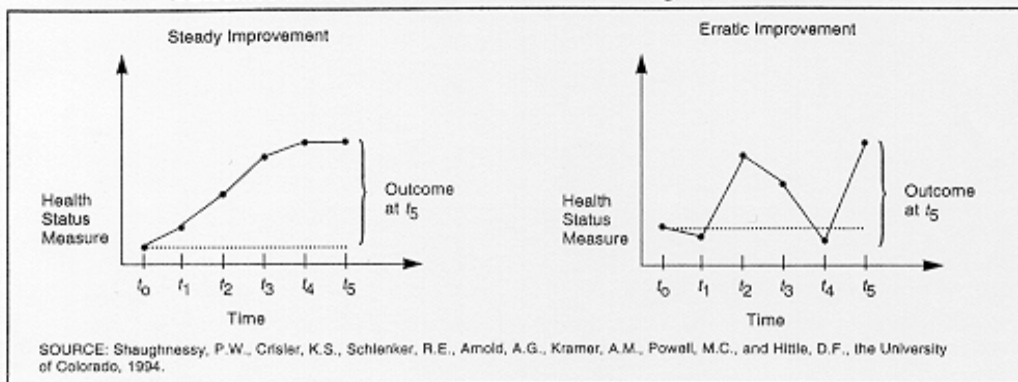
**Figure 1**  
**Outcomes as a Function of Antecedent Care and Natural Progression of Condition (Disease or Disability)**



**Figure 2**  
**Potential Differential Effects of Outcomes of Care Relative to Timing of Followup Observations**



**Figure 3**  
**Outcomes in the Context of the Pattern of Change in Health Status**



Source: Shaughnessy et al. in Health Care Financing Review 16(1) 1994.

Some Australian clinicians have expressed concern about the timing of outcome measurement in rehabilitation of older persons, particularly those with cognitive and/or psychosocial issues. The question of attributing outcome to intervention, whether by individual disciplines or the entire multi-disciplinary team is considered to be a major one. Achievement of progress towards long-term goals is thought to be particularly difficult to attribute to rehabilitation therapies (NARI 2001: 24).

### **Utilisation outcomes**

Utilisation outcomes can be chosen to cover patterns of use of institutional and community services if pre- and post-intervention data capture is possible. The main utilisation outcomes of interest in this type of evaluation are 'avoidable' hospital admission and/or admission to institutional long-term care (for example Lim 2001, DHAC 2001, Weissman et al. 1992). Changes in the use of formal community-based services, general practice services and prescription medicines are other potential utilisation outcomes.

Large-scale Australian studies of post-acute and coordinated care have generally failed to demonstrate significant gains in utilisation outcomes (eg. Lim 2001; DHAC 2001). This might have been due at least in part to the heterogeneity of study groups and approaches to data collection and analysis that failed to account for important confounding variables. Some of the early international research in this field also failed to demonstrate the cost effectiveness of community care in terms of reduction in institutional care, although Greene (1993), who conducted one such study in the United States, pointed out that the level of nursing care available to clients is critical in achieving desired utilisation outcomes (cited in Kane et al. 1994: 133). More recent work overseas has used refined definitions of 'appropriate' or 'preventable' hospitalisation. This has facilitated the reporting of more meaningful differences in utilisation outcomes between population groups and changes in more relevant outcomes for older people.

A number of studies have identified factors that are associated with high rates of avoidable hospitalisations. Income, educational attainment and disease prevalence consistently emerge as predictors, even allowing for variation in access to primary care (for example Culler et al. 1998; Blustein et al. 1998; Weissman et al. 1992). Culler et al. (1998) used the individual as the unit of analysis in a small area analysis to examine whether the predisposing, enabling and need characteristics of individuals who experience a potentially preventable hospitalisation differed from those of individuals who did not experience one. This study was an application of the Andersen behavioural model of service utilisation. It revealed that, apart from the socioeconomic factors already mentioned, the risk of a preventable hospitalisation among frail older people is greater for individuals who report poor health status, those who have had coronary heart disease or myocardial infarction, or those with limitations in two or more activities of daily living. This excess risk was estimated to



account for up to 17% of Medicare beneficiaries in the United States (persons aged 65 or more years and persons aged less than 65 years who have a disability).

Preventable, or avoidable hospitalisations are commonly defined as admissions for conditions that can be managed effectively in an ambulatory setting – ‘ambulatory care sensitive’ conditions (a term coined by Billings et al. 1993 cited in Culler et al. 1998). Weissman et al. (1992) used a list of principal diagnoses thought to represent ambulatory care sensitive conditions based on three earlier studies. They conducted a clinical review to remove conditions for which the link between effective ambulatory care and hospitalisation was thought to be tenuous; because there was a lack of consensus; or because hospitalisation rates for a condition were thought to be related to disease prevalence and practice patterns. Added to the list were congestive heart failure, pneumonia and pyelonephritis. In recommending this list as a basis for defining potentially avoidable hospitalisation, the authors commented that ‘being avoidable is a matter of degree’. They suggested that defining avoidable hospitalisations in terms of ambulatory care sensitive conditions is most useful when one has access to prescribed norms. Further, they emphasised that it is necessary to distinguish between an admission that is discretionary from one that is avoidable.

Original lists of ambulatory care sensitive conditions were developed in the United States using data for patients aged less than 65 years, however some identified conditions such as pneumonia are common terminal events in older patients (Blustein et al. 1998). A large-scale study in the United States found that just four conditions accounted for over 70% of ambulatory care sensitive hospitalisations (excluding for pneumonia) of older people (Table 6). People aged 65 or more years are insured against health care costs under the U.S. Medicare system. Even after adjusting for level of comorbidity, the analysis revealed that U.S. Medicare beneficiaries with lower levels of educational attainment, lower income, more advanced age, a history of more chronic diseases and poorer self-rated health status were at significantly higher risk of preventable hospitalisation. Barriers to securing medications to control hypertension, diabetes or congestive heart failure were mentioned as possible risk factors for socioeconomically disadvantaged older people in the U.S. (Blustein et al. 1998).

Factors that have been found to influence older people’s use of formal home-based services following an acute episode include discharge ADL scores, prior use of community services, instrumental ADL impairments and low levels of social support (Kane et al. 1994: 132). Supply and demand factors have also been identified. In the United States, higher use of post-discharge home-based services has been observed in regions with higher hospital discharge rates and lower average length of stay (in hospital) (Kane et al. 1994: 132).

Prior use of services, both community and institutional care, is a marker of where a client is on the care continuum. For the pilot program evaluations, records of hospitalisation including emergency department visits, MBS, PBS and community services in the 6, or ideally, 12 months prior to referral would give an indication of risk for entry to a residential aged care facility. Client or informant reports are an acceptable compromise if official records are not available, although recall may not

provide enough detail on hospital admissions and emergency department presentations.

**Table 6: Principal diagnoses in preventable hospitalisations for ambulatory care sensitive conditions<sup>(a)</sup>, United States, 1992**

Principal diagnosis	Per cent of avoidable hospitalisations
Congestive heart failure	32.2
Angina pectoris	16.3
Chronic obstructive pulmonary disease	11.6
Kidney/urinary tract infection	10.6
Dehydration/volume depletion	7.3
Type 2 diabetes mellitus	5.0
Asthma	5.0
Gastroenteritis	2.8
Cellulitis	2.5
Grand mal and other convulsions	2.3
Hypoglycaemia (unspecified)	1.3
Skin graft with cellulitis	1.3
Severe ear, nose or throat infection	0.8
Hypertension	0.5
Type I diabetes mellitus	0.5
<b>Total (excluding dental)</b>	<b>100.0</b>

(a) Based on 398 preventable hospitalisations experienced by 316 elderly patients from billing data for 7,303 community-dwelling US Medicare beneficiaries aged 65 years or more.

Source: Blustein et al. 1998.

## End-result outcomes

### *Physical functioning*

Mauser and Miller's outcome classification shown in Table 4 focuses end-result outcomes on measures of function. Gallo et al. (2000: 101) suggest that functioning in daily life can be examined on several levels:

- performance in personal care tasks, or activities of daily living (ADL), such as eating, bathing, dressing and grooming.
- performance in every day tasks, or instrumental activities of daily living (IADL), such as shopping, using the telephone, using transport, preparing meals; and
- performance in social and occupational roles.

These levels conform to Maslow's (1970) hierarchy of human needs and correspond to the activity and participation domains of the International Classification of Functioning, Disability and Health.

Outcomes on the first and second levels are typically assessed using standard ADL and IADL scales. The Functional Independence Measure and Barthel Index are two widely used ADL scales and a smorgasbord of IADL instruments is available for measuring functioning in higher order activities. Some instruments combine ADL and IADL domains on the one scale. ADL scales are known to exhibit ceiling effects when used to measure functional status of community dwelling older adults. Gallo et al. (2000) consider IADL measures to be a more “fruitful” functional assessment of ambulatory older persons. They associate the term ‘frailty’ with ADL performance qualified by an individual’s “assets” and “deficits”. The presence or absence of carer burden and the person’s resources, attitudes and health status define their assets and deficits. A change in one domain can “tip the balance into frailty”.

The Home and Community Care dependency data items project developed functional screening and functional assessment instruments based on performance in activities of daily living and instrumental activities of daily living (CHSD 2001). The 9-item National HACC Functional Screening Instrument incorporates items from the IADL sub-scale in the *Older American Resources and Services Multidimensional Functioning Assessment Questionnaire (OARS MFAQ)*. Two items in the OARS MFAQ IADL scale (ability to use the telephone and prepare own meals) are not in the HACC screening instrument and two OARS ADL items (walking, bathing/showering) are included (Box 1). The omission of meal preparation and telephone use could be a serious oversight in an evaluation context. LaPlante, Harrington and Kang (2002) found that preparing meals was a highly significant IADL factor in the prediction of both paid and unpaid hours of care reported in the U.S. National Long Term Care Survey. Meal preparation and walking were the strongest IADL factors in predicting secondary unpaid hours of care. Telephone use was a significant predictor of paid care and unpaid primary care. Although the fewest number of persons in the survey received help to use the telephone (weighted to an estimated long-term care population of 1.3 million people), they received an average of 87.2 total hours of help per week, which was the highest average recorded against any IADL factor.

As with the OARS scale, the HACC screening instrument records performance in each activity according to whether the activity can be performed independently, only with help or not at all. Two items to screen for potential behaviour and cognition problems that are not part of the OARS MFAQ scale are included in the HACC screening instrument. These are recorded by observation, not direct questioning of the client and, depending on the answer, could trigger a more detailed behavioural or cognitive assessment. In summary, the HACC functional screening instrument is a collage of items from ADL, IADL, cognitive and behavioural domains. This instrument is already used in the *Personal Alert Victoria* program (DHS 2003) and is being trialed by many HACC service providers throughout Australia. HACC officials have endorsed the 9 dependency data items from the functional screening instrument for inclusion in Version 2 of the HACC data dictionary. Version 2 is due to go live in July 2005.

### **Box 1: National HACC Functional Screening Instrument**

#### **Part One: Questions to ask the client (or person representing the client):**

1. Can you do your housework? [2] without help [1] with some help [0] unable to do housework
2. Can you get to places out of walking distance?...
3. Can you go shopping for groceries or clothes (assuming you have transportation)?...
4. Can you take your own medicine?...
5. Can you handle your own money?...

[Do not ask the following 2 questions if the client scored 2 on all of the above 5 items. Instead, for clients who scored 2 on all of the above items, record a score of 9 on each of the following 2 items.]

6. Can you walk?...
7. Can you take a bath or shower?...

#### **Part Two: Questions for case manager to complete**

8. Does the person have any memory problems or get confused?
9. Does the person have behavioural problems for example, aggression, wandering or agitation?

*Source:* CHSD 2001: Appendix 8

Depending on the score from the functional screen, the National HACC Functional Assessment Instrument is administered. This comprises a self-care (ADL) instrument, Modified Barthel Index (10-items maximum 20 points, Collins scoring), a domestic functioning assessment (modified Lawton's IADL scale) and a behavioural assessment using items from the Australian Resident Classification Scale, adapted for use in a community setting. The Mini-Mental State Examination (community version) has been recommended for HACC cognitive assessment. There is currently no plan to include scores from the national HACC functional assessment instrument in the minimum data set.

The Innovative Pool evaluation framework should ideally specify pure ADL and IADL scales that have been tested for reliability, content and construct validity. Although the national HACC functional screening instrument is an adaptation of the OARS IADL scale, it omits one item from that scale corresponding to a specific service type – ability to prepare one's own meals – and a second item on use of the telephone that has to do with ability to seek assistance. In the context of screening, this might not be a serious omission because the full HACC domestic functioning assessment covers all domains of instrumental activities of daily living. For program evaluation, however, it is essential to cover all major domains as economically and reliably as possible. With the addition of these two items from the original OARS IADL scale, the evaluation would have access to both comparative data and data generated from an internationally respected, valid and reliable scale for domestic functioning. The potential to generate comparative data is the main factor recommending use of the functional screening instrument in the pilot services evaluation.

In practice, it is important to recognise that theoretical considerations need to be weighed against the advantages of adopting tools that are consistent with national standards or State and Territory guidelines for the delivery of aged care and disability services. The advantage of the unmodified OARS IADL scale is that it is the only IADL instrument that will not involve considerable duplication of effort for service providers and also produces scores that are reported to be correlated with formal service use, in particular, entry to long-term residential care. If it proves impractical to construct equivalent comparison groups, then an evaluation using only reflexive controls (before and after measurements but no comparison group) would benefit greatly from outcomes based on tried and true measures. On the other hand, adoption of a scale that is not widely used, however valid and reliable, will limit opportunity to use external sources of data for impact evaluation ie. to perform an *ex post* quasi-experimental evaluation. It is judged necessary to include the HACC dependency data items in the set of evaluation outcome measures for the purposes of comparative evaluation. In addition, the missing domestic functioning items (meal preparation and telephone use) from the OARS MFAQ scale should be collected to generate a pure IADL score of international repute. Essentially, this means using the OARS MFAQ IADL scale (subject to copyright permission) as the basis of client IADL outcome measurement, whilst allowing for the possibility of cross-program comparisons through the HACC functional screening instrument.

For core outcome measures, standardisation across the pilot sites is preferred if the evaluation is to be truly national rather than a collation of State- and Territory-level evaluations. The degree of prescription in each measure depends on how critical the measure is to the national evaluation. Although instrumental ADL outcomes are perhaps more critical than ADL outcomes in the community setting, the literature also tells us that ADL limitations, particularly incontinence, are important predictors of utilisation outcomes. Unless standard assessment of client health outcomes are chosen for the evaluation framework, it will be difficult to compare client groups at baseline, and to draw conclusions about how differences in service utilisation might relate to differences in client profiles at baseline.

Notwithstanding their known ceiling effects and lack of sensitivity to long-term outcomes, the FIM and the Barthel Index are obvious candidates for measuring self-care outcomes. Capacity for self-care is an important marker for the continuum of care model. The FIM is an internationally accepted measure in rehabilitation medicine and is recommended by the Australian Faculty of Rehabilitation Medicine. FIM physical items are based on the Barthel Index but the FIM also covers social interaction, problem solving and memory (McDowell & Newell 1996: 115). These additional items offer no distinct advantage if cognitive and behavioural domains are addressed by other core assessments. In fact, it has been suggested that the social and communication dimensions of the FIM have low sensitivity (McDowell & Newell 1996: 120). The Barthel Index measures functional independence in personal care and mobility. It was developed to monitor performance in chronic patients before and after treatment and to indicate the amount of nursing care needed (McDowell & Newell 1996: 56).

Of the two instruments, the FIM is the more widely used for administrative reporting throughout Australia at present. Assessment should be carried out by a FIM certified assessor. There is some concern about the subjectivity of scoring even when people are appropriately trained (NARI 2001: 26). A factor recommending the Modified Barthel Index is its inclusion in the National HACC Functional Assessment Instrument (although it is not a HACC minimum data set item). This increases the possibility that self-care scores from the Barthel Index will have been collected for clients who entered pilot programs prior to specification of evaluation data requirements. Both the FIM and Barthel Index (original) are recommended functional assessments in the draft National Framework for Documenting Care in Residential Aged Care Services, along with Katz IADL and the Physical Mobility Scale (DHA 2003). A survey of key rehabilitation centres in Victoria revealed that services with a geriatric evaluation and management focus tended to favour the Barthel Index, while services with a stronger rehabilitation focus favoured the FIM. Local administrative reporting requirements were a further determining factor.

Threshold values for determining independence sufficient to live in the community have been published for versions of the Modified Barthel Index (McDowell & Newell 1996). However, McDowell and Newell recommend that the Barthel Index should not be used in isolation to predict outcomes because of its narrow scope. ADL functioning is an important core assessment, however, and the 20-point Modified Barthel Index (Collins scoring) is the preferred choice for this domain of measurement in the national evaluation, mainly because it has been recommended for the National HACC Functional Assessment framework.

Participation outcomes are perhaps as critical as functional outcomes, particularly for people whose disability is long-standing but for whom a change in circumstances or recent decline in physical condition has increased their handicap. Functional outcomes may need greater emphasis in pilots servicing a post-acute clientele but it should be noted that ADL outcome measures in post-acute clients are sensitive to the timing of baseline measurements, which will vary according to hospital discharge planning. Delays between client assessment and placement will also have an impact on post-acute ADL measures.

The International Classification of Functioning, Disability and Health (ICF) places 'participation' with 'body' and 'activity' as the three main components of functioning and disability. Activity is defined as the execution of a task or action by an individual, whereas participation is defined by involvement in a life situation. Involvement implies a sense of being autonomous to some extent: either by performing an activity independently, with assistance, or by directing the way an activity is performed on your behalf (Perenboom & Chorus 2003). In this sense, measures of activities of daily living function could be considered intermediate-result outcomes for the end-result outcomes of extent of participation and satisfaction with participation (AIHW 2003b). The concept of participation is very relevant to older people with a disability who may have long-standing functional limitations that are unresponsive to therapy. For many, the prospect of significant

improvement in areas of functioning will be limited yet small changes in environment, confidence and access to assistance can greatly improve their capacity to participate in community life. Activity restriction and participation data elements in the National Community Services Data Dictionary and Aged Care Assessment Program Data Dictionary could be used to generate nationally comparative data on activity restriction and participation (Table 7; see also AIHW 2002a and AIHW 2000b).

### **Subjective measures of health status and health-related quality of life**

While it is generally agreed that subjective measures of health status should be included in evaluations, practical difficulties are also acknowledged. These measures, which have strong foundations in the quality of life literature, are typically recorded through self- or observer-report and tend to be highly subjective even when collected with a standard instrument. Depending on the purpose of the evaluation, they can be classified as end-result or intermediate-result outcome measures. Broad measures of health status focus on individuals' subjective perceptions of their health (Bowling 1997: 38). Hunt, cited in Bowling (1997), defines perceived health as an individual's experience of mental, physical and social events as they impinge upon feelings of well-being. Simple measures of perceived health are related to use of health services, mortality and rates of recovery from illness (Bowling 1997; Eagar et al. 2002).

Health-related quality of life covers the subset of quality of life domains that are affected by a health status or which can be modified by a health intervention. This distinction is useful in highlighting the focus of assessment but is often not easy to make in the context of aged care (Bond 1999). Quality of life is recognised as an important outcome to be measured in evaluation research of chronic disease and illness, however there has been little systematic attempt to clarify and define the concept as it relates to older age or to people with dementia. Bond (1999) highlights two principles as having emerged from social gerontology research. Firstly, factors that define a good quality of life for older people are also relevant to people from other age groups. Secondly, the experience of being an older person in contemporary society is determined as much by economic and social factors as by biological or individual characteristics.

**Table 7: Activity and participation data items, National Community Services Data Dictionary Version 3 (draft) and Commonwealth-State/Territory Disability Disagreement Data Dictionary Version 1.0**

Data element	Definition	Data domain <sup>(a)</sup>
Activity and participation domains	Life areas in which individuals may participate or undertake activities.	1 Learning and applying knowledge 2 General tasks and demands 3 Communication 4 Mobility 5 Self-care 6 Domestic life 7 Interpersonal interactions and relationships 8 Major life areas 9 Community, social and civic life
Activity – level of difficulty	<p>The level of difficulty that an individual has in executing an activity. Activity is the execution of a task or action by an individual. Activity limitations are difficulties an individual may have in executing an activity.</p> <p>Activity limitation varies with the environment and is assessed in relation to a particular environment; the absence or presence of assistance, including aids and equipment, is an aspect of the environment</p>	0 No difficulty 1 Mild difficulty 2 Moderate difficulty 3 Severe difficulty 4 Profound difficulty 9 Not stated/inadequately described
Activity and participation—support needs	The type and level of assistance a person needs with specific Activities and Participation areas. This data element is recorded and reported in conjunction with <i>Activities and Participation areas</i> to enable comparison of the support needs of pilot program clients with the CSTDA service user population and with Australian Bureau of Statistics (ABS) population data.	1 Unable to do or always needs help or supervision in this life area. 2 Sometimes needs help/supervision in this life area. 3 Does not need help or supervision in this life area but uses aids and/or equipment. 4 Does not need help or supervision in this life area and does not use aids and/or equipment. 5 Not applicable (only for use where the need for support or assistance is due to the person's age, not their disability. See Guide for use for more detail). 9 Not stated (not for use in primary data collections)
Participation extent	<p>Participation extent is the degree of participation by an individual in a specified life area.</p> <p>In the context of health, participation is involvement in a life situation. Participation restrictions are problems an individual may experience in involvement in life situations.</p> <p>This data element may be used to describe the extent of participation in life situations for an individual with a disability. The standard or norm to which an individual's participation is compared is that of an individual without a similar health condition in that particular society.</p>	0 Full participation 1 Mild participation restriction 2 Moderate participation restriction 3 Severe participation restriction 4 Complete participation restriction 8 Not applicable 9 Not stated/inadequately described

(continued)



**Table 7 (continued): Activity and participation data items, National Community Services Data Dictionary Version 3 (draft) and Commonwealth-State/Territory Disability Disagreement Data Dictionary Version 1.0**

Data element	Definition	Data domain <sup>(a)</sup>
Participation satisfaction level	<p>A person's level of satisfaction with their participation in an area of life, in relation to their current life goals. Participation restrictions are problems an individual may experience in involvement in life situations.</p> <p>This data element may contribute to the definition of disability and give an indication of the experience of disability from a personal perspective.</p>	<p>0 High satisfaction with participation</p> <p>1 Moderate satisfaction with participation</p> <p>2 Moderate dissatisfaction with participation</p> <p>3 Extreme dissatisfaction with participation</p> <p>4 No participation</p> <p>5 No participation and none desired</p> <p>8 Not applicable</p> <p>9 Not stated/inadequately described</p>

(a) Each data domain can be further broken down by 2-digit detailed categories in the Data Dictionary (not shown here).

Table 8 lists some factors related to quality of life relevant to older people with specific reference to factors identified by community-dwelling older people with mild to moderate dementia in a study by Bamford and Bruce (2000). Recurrent themes to emerge in discussions with service recipients and their carers was the importance of having a sense of autonomy and the level of control that was afforded by being able to live at home. Service quality was assessed in terms of both the service that was delivered and the service process (best viewed as process, rather than outcome, measures). Choice and autonomy featured heavily in this context. Bond and Corner (2001) caution against evaluating dementia care from a narrow biomedical perspective and recommend methods appropriate to the investigation of complex social phenomena for the study of a complex syndrome such as dementia.

Some of the better known health-related quality of life scales eg. Short Form 36 (SF36; Ware and Sherbourne 1992) and the Sickness Impact Profile (SIP; Bergner et al. 1981), have been developed on the premise of a strong relationship between functional limitation and quality of life, with items chosen from a professional rather than lay perspective. However, Bond (1999) gives the example that, to a young able-bodied person, functional decline may be seen as severely impacting on quality of life. Whereas, the older person might have come to terms with functional decline as an ongoing reality and will therefore have an entirely different outlook on quality of life and how it can be achieved.

**Table 8: Domains relevant to the quality of life of older people**

Domain	Dimensions	Empirical evidence in dementia <sup>(a)</sup>
Health status characteristics	Physical well being, functional ability, mental health.	*
Clinical characteristics	Diagnosis, prognosis, symptoms, medication and side effects.	
Physical environmental factors	Standard of housing or institutional living arrangements	
	Control over physical environment	*
	Access to facilities such as shops	
	Access to public transport	
	Access to leisure providers	
Social environmental factors	Family and social networks and support	*
	Social integration in the local community	*
	Levels and variation of recreational activity	*
	Safety and security	*
	Contact with statutory and voluntary organisations	
Socio-economic factors	Income and wealth	*
	Management of financial affairs	*
	Nutrition	*
	Overall standard of living	
	Ability to make choices	*
	Ability to exercise control	*
	Ability to negotiate own environment	*
Subjective satisfaction	Global quality of life as assessed by individual older person	
Personality factors	Psychological wellbeing	
	Morale	
	Life satisfaction	
	Happiness	
Cultural factors	Age	
	Gender	
	Ethnicity	
	Religion	

Source: Adapted from Bond 1999: Table 1.

(a) Dimensions of quality of life marked with an asterisk were specifically mentioned by community-dwelling service recipients with dementia in the United Kingdom (Bamford & Bruce 2000)

Practical difficulties have been encountered in recording reliable assessments for study participants with intellectual or cognitive impairment. Coen et al. found that a widely used scale in quality of life measurement was too complex for people with cognitive impairment or learning disabilities to interpret. "The nature of dementia as a degenerating condition involving cognitive impairment is perceived as a major

barrier, since memory, reasoning and speech and language difficulties militate against understanding and self report although these may still be appropriate for people in the early stages of dementia" (cited in Bond 1999). Cognitive decline will inevitably compromise rates of follow-up even when a reliable pre-intervention assessment of quality of life has been recorded. Finally, there is a correlation between poor mental health status and perception of health status and health-related quality of life. The relationship between the two is not well understood and this leads to difficulties in interpreting results.

In dementia and disability research, professionals and carers are often called on to make proxy judgements of client outcomes. Proxy information is reliable for certain measurement domains, predominantly those related to physical status and functioning (Burns et al. 1992), but are a generally poor substitute for self-reports of quality of life and health status (Ostbyte et al. cited in Bond 1999). Bond (1999) concludes that "the use of proxy informants to assess subjective elements of quality of life would therefore seem inappropriate, although significant others can have their own view about a subject's life quality. Methods to overcome these barriers remain in the early stages of development and there is little in the literature by way of validation."

Given the difficulties associated with perceived health status and quality of life measurement for these client groups, it may be more appropriate to focus on measures of participation and for those who are able to make a value judgement, satisfaction with their extent of participation.

### **Carer outcomes**

A report on the care of frail older people acknowledges that, across the OECD, the presence of a single main carer – the primary carer – is often the most important form of support. Servicing the needs of carers to ensure that they are able to maintain their crucial role in the balance of care is viewed as central to ageing in place and positive ageing policies (OECD 1996: 63, 76).

The 1998 ABS Survey of Disability, Ageing and Carers revealed that informal carers are the main source of support for most older people and younger people with a disability in need of assistance in Australia (ABS 1999). In 1998, 450,900 persons were identified as primary carers according to the Australian Bureau of Statistics and this number is projected to have increased to over 490,000 in 2002 (unpublished AIHW report on informal care). Direct caring activity involved more than 20 hours per week for over one-half of primary carers in 1998, and 40 or more hours per week for around one-third of primary carers. An estimated 29% of primary carers in 1998 were aged 60 years or over. The caring role can be arduous and relentless. It has long been recognised that an immediate consequence of a breakdown in carer physical and psychological health can be the need for an older person to enter a residential aged care facility (Isaacs et al. 1971, Zarit et al. 1980; Robinson 1983; LoGiudice et al. 1995). Home care of the person with dementia is associated with particularly high risk of carer breakdown and public preference for institutional care (Philp et al. cited in Dello Buono et al. 1999). The active participation of family carers in the design of care

programs and processes is crucially important in pursuing the goals of ageing in place and normalisation (OECD 1996: 63, 77).

Carer burden has been defined as “the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults” (George & Gwyther 1986 in Murphy, Schofield & Herrman 1992). ‘Objective’ burden includes observable disruptions or changes to family or personal life of the carer. ‘Subjective burden’ encompasses a carer’s personal response to and feelings about these changes and disruptions (Murphy, Schofield & Herrman 1992). Subjective burden in particular, is associated with carer feelings of inadequacy, incompetence, and inability to cope.

In Australia, carer burden is a major factor in the use of community services and residential aged care services of people with dementia (LoGiudice et al. 1995). Assessment of burden is included in guidelines for Personal Alert Victoria, a state government program to assist frail, older people and people with a disability who live in their own homes (DHS 2003). It is an outcome measure in the Australian Government Department of Veterans’ Affairs Community Nursing Guidelines (DVA 2003) and can be found in guidelines for Divisions of General Practice (eg. CDGP 2003). General practitioner referral of a patient for aged care assessment is perceived as an important threshold event for many carers who are no longer able to cope with the strain of their caring role (Bruce et al. 2002).

Caring for a person with dementia has been linked to increased risk of burden among primary carers. Dello Buono et al. (1999) reported that the main causes of potential burden in dementia care the heavy personal care needs, memory problems and challenging behaviours that can be experienced in the middle and late stages of dementia. Evidence of the relationship between challenging behaviour and carer burden is equivocal. A study by Zarit et al. (1980) found no association between challenging behaviour and level of burden. Vernooij-Dassen et al. (1996) found a strong association between carers’ sense of competence and agitation and apathy in the care recipient with dementia. They concluded that interventions that help carers recognise, clarify and understand the behaviour of the person with dementia might change the carer’s perception of the behaviour. This could increase the carer’s sense of competence and so reduce carer burden.

A link between carer burden and challenging behaviour in care recipients with dementia has been confirmed in several Australian studies (eg. Bruce & Paterson 2000; Schofield et al. 1998). This work has also reported on important contributing and mitigating factors. Schofield and colleagues noted the coincidence between problem behaviours and greater functional dependence, both in activities of daily living and in instrumental activities of daily living. Carer burden was significantly lower among carers of people with physical impairment, compared to carers of people with cognitive impairment or memory loss. Depression in carers of people with a psychiatric disorder was mediated by the presence of a carer confidante. Both studies reported that a firm diagnosis of the care recipient’s condition often reduces carer burden. Wood and Rabins, cited in Schofield et al. (1998), independently maintain that if carers understand the condition they are less inclined to interpret

behaviour as offensive or as the product of their own inadequacy. Hence, there are two aspects to the evaluation of outcomes in the treatment of problem behaviour. One is the impact of intervention on the behaviour itself and the other is whether the intervention has addressed the carer's understanding of, and ability to cope with, problem behaviour.

Despite a wealth of published information on the subject, it appears that the most frequently consulted health practitioners might not be well equipped to recognise and deal with the problem of carer burden. Interviews of Australian dementia carers who had relinquished their home-caring role revealed that all had experienced prolonged difficulty accessing services (Bruce & Paterson 2000). Specific difficulties that were reported include:

- Ignorance among general practitioners of service availability.
- General practitioners' insistence that institutional care was the only option when the family would have liked to continue at home.
- Carer reluctance to fully discuss the problems at home.

Continuing carers in the study also reported difficulty in accessing services after their initial contact with an Aged Care Assessment Team (ACAT). The ACAT was not perceived as a source of ongoing referral for accessing community services. Anecdotes highlighted the need for case management to establish ongoing service relationships (Bruce & Paterson 2000). An assessment of care recipient outcomes over the short-term without regard for how interventions might improve the longer-term capacity of carers to access and benefit from community services is likely to be of limited value. Innovative care pilot services could yield valuable information on how to reduce barriers to community services for clients and carers.

In the past, carer respite has been the main mechanism for addressing feelings of burden (Bruce & Paterson 2000). Formal respite services under the auspices of the National Respite for Carers Program, other national programs and State/Territory initiatives have expanded considerably since the mid-1990s in response to the needs of growing numbers of people providing care to highly dependent older people. While relief from the constant demands of caring is a pressing need for many carers, the effectiveness of respite in reducing carer burden is not well understood.

Studies of the efficacy of carer respite have failed to report consistent outcomes and patterns of carer response (Bruce & Paterson 2000; Zarit et al 1999). The results are relevant to the present study in that they reflect psychosocial dimensions of dementia care that are likely to surface among people participating in the innovative care pilots. A systematic review of 29 studies, including 11 studies of dementia carers, examined the evidence of the impact of respite care on carer well-being (McNally et al. 1999). Conflicting results led to a number of alternative observations about the effect of carer respite on the use of permanent residential aged care beds. Namely, respite care is variously reported to

- have the potential to postpone or even prevent entry to residential aged care facilities;

- offer a stark contrast to normal daily demands of caring, which may positively encourage families to choose residential aged care as a long-term solution;
- offer short-term gains in carer well-being which are not maintained in many cases because the respite period is not generally used to reinvigorate social relationships that would offer long-term support;
- have the potential to increase future strain in some situations by creating more problems that need to be managed after the period of respite.

Variation in empirical results might reflect the unique circumstances of carers and care recipients across study groups. Timing and type of respite play appear to be important factors. Deimling (1991) found that the effectiveness of respite intervention depended on the functional status of the care recipient with Alzheimer's disease. Carers of stable patients showed a benefit; carers who received respite when their care recipient was in a state of decline did not. Multi-modal interventions that promote or assist in the development of support mechanisms that extend beyond the respite period have tended to report more consistent positive results (Hinchcliffe et al. 1995; Mittelman et al., 1993). However, there are anecdotal reports from care workers assisting clients with dementia and their informal carers which suggest that the timing of client and carer interventions is crucial to the carer's decision to continue to provide care at home (personal communication). Once taken, the decision to admit a family member to permanent residential care might be irreversible even if a comprehensive package of community support is made available. This account concurs with that of Bruce and Paterson (2000) who have observed that referral of clients for community support often occurs too late and because of this referral to an ACAT is often quickly followed by admission to permanent residential aged care.

#### *Measuring carer burden*

Murphy, Schofield & Herrman (1992) reviewed a range of standard instruments for measuring carer outcomes relating to dementia care. They included a number of carer burden scales that are widely used today. Recalling that carer burden is defined in terms of objective and subjective burden, the authors suggest that a good instrument taps into both dimensions. In practice, instruments vary according to whether they measure only one or the other, or both. Instruments that measure both subjective and objective burden can be further distinguished by whether they include separate subscales for the two dimensions or not. On theoretical grounds, the review recommended two scales, the Caregiver Burden Inventory (Novak & Guest 1989) and the Cost of Care Index (Kosberg & Cairl 1986) and expressed a preference for the former. As at the date of the review, the Caregiver Burden Inventory had been demonstrated to have acceptable reliability but there was no data on its validity. The Cost of Care Index had demonstrated acceptable reliability and was undergoing validation.

Of the ten standard instruments included in the review, two are more widely reported in the Australian literature on informal care. Robinson's (1983) Caregiver Strain Index combines objective and subjective burden on the one scale, with a

possible bias towards the objective. Reliability and construct validity testing was undertaken at the time of scale development and the results have been published. The Index was developed using responses from 85 individual carers of older patients who had returned home after hospitalisation for a major episode of illness or surgery. This 13-item self-report scale is included in the Australian Government Department of Veterans' Affairs outcome measurement guidelines and in the Queensland ONI assessment guidelines. There is some concern in the field that it does not adequately capture the extent of the caring experience. A longer instrument, the Zarit Burden Interview, is widely reported in the informal care literature (Zarit et al. 1980). This 29-item instrument combines subjective and objective burden on the one scale. The Burden Interview was developed for a study of the correlates of carer burden in dementia care (dementia patients and their primary carers). It has acceptable reliability (Murphy, Schofield & Herman 1992). Many other instruments have been developed specifically for use in individual studies. For example, the Alzheimer's Association of Australia Memory Loss Support Groups Evaluation used a purpose-designed questionnaire for carers of people with memory loss. While these instruments have been well received in the field, not all have been subjected to rigorous psychometric testing.

Some standard instruments that measure memory loss and challenging behaviours in dementia patients capture the level of carer distress caused by each type of behaviour (Neville & Byrne 2001). For the Innovative Pool evaluations the AIHW recommends either of two approaches to the measurement of carer burden.

1. Adopt the Carer Strain Index (CSI) to measure (primarily) objective burden. Supplement this with subjective measures of burden taken from one of the standard instruments for dementia behaviour outcomes eg. Revised Memory and Behavior Problems Checklist (Teri et al. 1992) that correspond to behaviour items on the Resident Classification Scale; or
2. Use an instrument for problem behaviours that generates a score that is known to correlate with feelings of burden eg. Dementia Behavior Disturbance Scale (Baumgarten et al. 1990).

Option 2 is perhaps not appropriate for carer assessment in the disability services pilots because the instrument was designed specifically to measure dementia-related correlates of carer burden. The Dementia Behavior Disturbance Scale is a useful scale for carer outcome measurement in dementia care. It covers passive behaviours that are potentially stressful to family members. Option 1 involves two scales, and therefore, administrative overhead. The Revised Memory Behavior Problems Checklist measures observable and potentially modifiable behaviours. It is administered to the carer or individual familiar with the person with dementia to quantify behaviour, agitation and depression and the carer's reaction to each of the behaviours (Neville & Byrne 2001). Given the difficulty that will be associated with self-report of depression by clients participating in the dementia pilot program evaluation, a carer/observer assessment using an instrument such as the Revised Memory Behavior Problems Checklist will probably be necessary. If so, there is no added overhead in using such a tool to measure subjective carer burden, although

some dimensions of subjective burden might be missed. The AIHW has been informed that none of the standard dementia behaviour instruments has been demonstrated to be universally appropriate for use with people from culturally and linguistically diverse backgrounds and at the present time there appears to be no widely recommended scale or scales for these groups.

A modified version of the Australian Aged Care Resident Classification Scale behaviour sub-scale incorporating the carer reaction scale from the Revised Memory and Behavior Problems Checklist represents a compromise between use of a standard, validated instrument, adherence to national standards and administrative burden (Box 1). Service providers can adapt the wording of items for populations that they are working with as long as the questions retain the original meaning.

A general assessment of carer psychological well-being would be desirable to tap into recent changes in carer disposition that might be attributable to care recipient functional decline and/or hospitalisation. This assessment should identify the specific nature of any psychological distress, since the pilot program interventions may provide considerable support to carers. For this purpose, the General Health Questionnaire (Goldberg 1972) is recommended. The original GHQ was developed as a 60-item self-administered instrument to identify firstly, inability to carry out normal 'healthy' functions and secondly, the appearance of new phenomena of a distressing nature (Goldberg cited in McDowell & Newell, 1996: 225). It covers four elements of distress: somatic symptoms, anxiety and insomnia, social dysfunction and depression. Long and short forms of the GHQ have excellent reliability and validity results and the instrument is used widely throughout the world (Gallo et al. 2000; McDowell & Newell 1996). The 28-item GHQ (GHQ-28) provides a score for each of the four subscales for use in studies that require more detail than an overall score of mental health. Respondents are asked to assess whether they have recently experienced each feeling using a four-point Likert scale. Responses allow the person to assess current state relative to how they perceive their usual state (eg. Not at all/No more than usual/Rather more than usual/Much more than usual).



### Box 1: Modified RCS behaviour sub-scale

#### Client behaviour rating scale:

- [0] No difficulty – requires no assistance.
- [1] Some difficulty – occasionally – requires monitoring but not regular supervision.
- [2] Intermittently – requires monitoring for recurrence and then supervision on less than a daily basis.
- [3] Extensively – Requires monitoring for recurrence and supervision on a daily basis.

#### Carer reaction rating scale:

- [0] Not at all
- [1] A little
- [2] Moderately
- [3] Very much
- [4] Extremely
- [9] Don't know/not applicable

1. **Memory loss** – This question refers to asking the same question over and over, trouble remembering recent or significant past events, losing or misplacing things.  
Client behaviour rating [ ] Carer reaction rating [ ]
2. **Sense of loss of self** – This question covers expressed feelings of loss of self, sadness, depression, loneliness, crying and tearfulness, lack of interest in activities once enjoyed, over sleeping.  
Client behaviour rating [ ] Carer reaction rating [ ]
3. **Problem wandering or intrusive behaviour** – This question relates to the care recipient wandering, absconding or, whilst wandering, interfering with other people or their belongings.  
Client behaviour rating [ ] Carer reaction rating [ ]
4. **Verbally disruptive or noisy** – This question includes abusive language and verbalised threats directed at a care recipient, visitor or member of staff.  
Client behaviour rating [ ] Carer reaction rating [ ]
5. **Physically aggressive** – This question includes any physical conduct that is threatening and has the potential to harm a care recipient, visitor or member of staff.  
Client behaviour rating [ ] Carer reaction rating [ ]
6. **Emotional dependence** – This question is limited to the following behaviours: active and passive resistance other than physical aggression: frequently expressed feelings of loss of self, sadness, loneliness, crying or tearfulness; withdrawal, including lack of interest in activities and over sleeping; attention seeking or manipulative behaviour.  
Client behaviour rating [ ] Carer reaction rating [ ]
7. **Danger to self or others** – This question covers high-risk behaviour which includes behaviour requiring supervision or intervention and strategies to minimise the danger.  
Client behaviour rating [ ] Carer reaction rating [ ]
8. **Other behaviour** – This question covers behaviour not already covered in questions 1 to 7 that requires staff to spend time and effort in addition to support for daily activities.  
Client behaviour rating [ ] Carer reaction rating [ ]

Sources: Adapted from the Australian Aged Care Resident Classification Scale (client behaviour items and rating scale) and the Revised Memory and Behavior Problems Checklist (carer reaction scale) (Teri et al. 1992)

## Process outcomes

Client outcomes can be affected by the way in which care is delivered. Process measures help to explain associations between interventions and outcomes.

Examination of process can also help to explain exceptions to general patterns of response and identify quality of care problems. Picker Institute Europe (formerly the Picker Institute of the United Kingdom) consulted over 8,000 patients, their families, physicians and hospital staff over 7 years to develop an instrument to measure patient satisfaction with health services. The goal was to determine what patients wanted, what they valued, what helped or hindered their ability to manage their health problems, and what aspects of care were most valuable. The results of these interviews were used to identify 8 dimensions of client-focused care:

1. Respect for client values, preferences and expressed needs.
2. Information and education.
3. Access to care.
4. Emotional support.
5. Involvement of family and friends.
6. Continuity and transition.
7. Physical comfort.
8. Coordination of care.

Process measures seek to measure quality of care and care delivery. A number of studies of in-home health services for older people in the United States have identified the following service provider problems that impacted on quality of care (reported in Kane et al. 1994: Table 1):

- Case managers not seeking to remedy remedial conditions.
- Rough care.
- Home health aides deficient in basic knowledge.
- Essential services unavailable.
- Not enough qualified personnel to meet demand.
- Inappropriate match of personnel and client.
- Care too expensive.
- Worker insensitivity, disrespect, or intimidation of client.
- Inadequate plan of treatment.
- Inadequate coordination of patient services.
- Inadequate clinical care.
- Post-hospital care not received according to guidelines for time of initial visit and intensity of service.
- Worker tardiness, no-shows or early departures.

- Attendants not available at hours needed or long enough.
- Client has insufficient control over selection, job definition, and supervision of attendant.
- Client not confident workers will be available for as long as they are needed.

The delivery of community-based care in people's homes presents a unique set of challenges in quality of care measurement. In home care, the service provider is a guest of the patient and has less control over the physical and social environment than in a residential care setting. Thus, in addition to those problems listed above, providers have reported client failure to perform or complete tasks adequately and failure to conform to physician's orders as contributing to suboptimal outcomes (Kane et al. 1994: Table 1).

Clark and Smith (1998) charted changes in patient satisfaction with rehabilitation progress over time in a study at the Repatriation General Hospital in Adelaide, South Australia. Factors found to influence satisfaction with progress included return to previous lifestyle activities, depression, family functioning, understanding of the medical condition, and clarity of expectations on admission to rehabilitation. This latter factor reflects on the experience of the Australian Coordinated Care Trials, in which many clients entered with unrealistic expectations of what the intervention could deliver.

In practice, satisfaction surveys tend to overestimate client satisfaction because people accessing services have a tendency to fail to report dissatisfaction or even to be averse to the experience of dissatisfaction when problems are encountered. A review of the literature by Cooper & Jenkins (1999) reported that the most useful methods of obtaining client feedback focus on specific aspects of the service, particularly the more impersonal, organisational aspects. Whereas indirect, global measures of satisfaction are unlikely to reveal problems or sources of dissatisfaction, direct measures of specific service attributes are more likely to identify service quality issues. While there is a need to seek patient views, inadequate or inappropriate survey instruments may not tap into real concerns (Butler et al. 2000).

Process evaluation requires the dates of significant events in the service delivery process to be recorded – client movements, referrals and the receipt of services corresponding to those referrals (for example, respite care) to present a more objective picture than merely generic questions about satisfaction. Attempts to measure process outcomes might usefully use these data to focus on specific aspects of service delivery: timely access to assistance and required services, efficiency of transfers, availability of required service types, effectiveness of case management and coordination, staff/therapist demeanour and continuity, affordability, information and communication, and practical issues such as transport.

### **3 Scope of outcome and process measurement**

In this section we present a set of core health status, functioning and utilisation measures that can be adopted as a basis for a national evaluation framework. The AIHW recommends that the national evaluation framework focus on outcomes for the measurement domains listed in Tables 9 and 10. 'Discharge support arrangements' in Table 9 refers to whether a client returns to another private residence as opposed to a residential aged care facility, and the nature of government program support which makes this possible.

The following sections outline a set of data collection modules. Key evaluation outcome measures can be calculated using data items in the modules. Modules contain other information to enhance the reporting of evaluation by providing service provider and client profiles (including data for describing the care continuum), and records of activity for each service type category. Frequency of data collection for each module will need to be specified in the national evaluation framework.

#### **3.1 Core outcome measures of health, function and utilisation**

In order to calculate core outcome measures, client assessment results will need to be recorded and supplied to the national evaluator. The minimum requirement is to record results at entry to and exit from the pilot services, however there is scope to specify additional assessment points in the framework because most providers will be performing regular client reviews according to their particular case management model. The literature suggests that 60-day intervals ie. bi-monthly review is a reasonable compromise for evaluation purposes. Multiple assessments would allow for an evaluation of interventions based on change in client status over time. This will strengthen the impact evaluation if valid control or comparison groups cannot be established. Pending production of the evaluation framework, the AIHW recommends that pilot sites be encouraged to record the required assessment results at client entry and approximately every 60 days thereafter. The national evaluation framework should specify the total period over which measurements are to be taken.

A client service event data set should record service events for each client to allow client-level costs to be generated. Client co-payments will need to be recorded in the client service activity profiles against each service event.

**Table 9: Core health outcome measures and instruments proposed for the Innovative Pool evaluations**

Domain	Instrument	Scope	Required scores
Client ADL	20-point Modified Barthel Index (Collins scoring)	All clients at entry, discharge and interim assessment points	10 item scores
Client IADL	HACC functional screening instrument <sup>(a)</sup> plus items on meal preparation and telephone use from the OARS MFAQ IADL scale	All clients at entry, discharge and interim assessment points	<ul style="list-style-type: none"> <li>• Scores for items 1–7 on the HACC instrument<sup>(a)</sup></li> <li>• Scores for meal preparation and telephone use items on the OARS MFAQ scale.</li> </ul>
Client behaviour	1. HACC functional screening instrument behaviour items  2. Adapted Resident Classification Scale behaviour sub-scale. A scale for carer subjective response rating is added to each item in the adapted scale.	All clients on entry  Measure on entry, discharge and interim assessment points for <ul style="list-style-type: none"> <li>• Clients in dementia care high care need or challenging behaviour pilots.</li> <li>• Other clients for whom a behaviour assessment is triggered by the HACC screening items.</li> </ul>	Scores for items 8 and 9  Scores for RCS items 9–14 and carer response score for each item if applicable.
Client cognitive functioning	Mini-Mental State Examination	All clients on entry and discharge	Total score
Carer burden	Carer Strain Index	All primary carers on entry, discharge and interim assessment points	Total score
Carer psychological well-being	General Health Questionnaire (28 item version)	All primary on entry, discharge and interim assessment points	4 sub-scale scores
Self- or observer-rated health status	As per OARS MFAQ physical health scale item or similar Likert scale	All clients on entry and discharge  All primary carers on entry and discharge	One rating eg. Excellent...poor
Extent of participation	National Community Services Data Dictionary V3 data item <i>Participation extent</i>	All clients on entry and discharge	Ratings for participation areas 1 to 9 (Table 7)
Satisfaction with participation	National Community Services Data Dictionary V3 data item <i>Participation satisfaction level</i>	All clients on entry and discharge	Ratings for participation areas 1 to 9 (Table 7)

(a) The HACC functional screening instrument contains ADL, IADL and items on behaviour and cognition. All 9 items should be collected to facilitate comparisons that may be possible with program data. The 5 true IADL measures which originate from the OARS MFAQ IADL scale, together with 2 further items on telephone use and meal preparation will facilitate an evaluation of client IADL outcomes using an instrument that has been tested for reliability and validity.

**Table 10: Utilisation outcome measures proposed for the Innovative Pool evaluations<sup>(a)</sup>**

Domain	Measure	Details
Emergency department presentations	Number	
Planned hospitalisations	Number/LOS (admission & separation dates)	Principal diagnosis AR-DRG (or surgical/medical)
Unplanned hospitalisations	Number/LOS (record admission & separation dates)	Principal diagnosis AR-DRG (or surgical/medical)
Potentially avoidable hospitalisations	Number/LOS (admission & separation dates)	Principal diagnosis AR-DRG (or surgical/medical)
Discharge support arrangements	Living arrangement Government-funded support programs	Data definitions from the National Community Services and ACAP data dictionaries

(a) For use in for within-subject before and after comparisons and comparing aggregate rates with external populations.

### 3.2 Client profiles

Client characteristics should be recorded at entry to the service (carer details are listed separately under client social resources profile). Profiles should include the following details for each client, consistent with national data definitions where applicable:

- Age
- Sex
- Marital status
- CALD characteristics
- Level of education attainment (for interpreting cognitive assessment results)
- Main source of income
- Health care concession card holder?
- Indicator of financial disadvantage as assessed by service provider
- Usual living arrangement
- Living arrangement at date of referral to pilot service
- Use of government funded community programs at entry to pilot service
- Indicator of waiting for placement in a residential aged care facility
- Indicator of whether client or carer has visited a residential aged care facility with a view to lodging an application
- Number of ACAT assessments in last 12 months

- Date of most recent ACAT assessment
- Most recent ACAT recommendation
- ACAP primary health condition code from most recent ACAT assessment
- Date of referral to pilot service
- Source of referral
- Date of admission to service
- Date of discharge
- Reason for cessation
- Total recreational leave days
- Total hospital leave days
- Discharge living arrangement
- Government support programs on discharge from pilot service
- Carer details on discharge
- Details of hospitalisations

### **3.3 Client health status**

Client health status should be recorded at entry to the pilot service and a subset of items should be recorded on discharge. Health status on discharge may not reflect the quality of care received because of factors intrinsic to the client and their home environment. However, it is recommended that self- or observer-rated health status and participation measures be recorded at both entry and discharge to be included as core outcome measures. One item in the client health status profile asks for a case manager or professional assessment of the client's level of restriction in core activities (self-care, mobility and communication). Although the ADL measures give similar information, collecting the level of restriction (handicap) as opposed to level of functioning (disability) will allow cross comparison with the population of older people with a severe or profound level of restriction as reported by the ABS Survey of Disability, Ageing and Carers.

Additional items on number of chronic conditions and key risk factors for entry to residential aged care are listed below. These form a recommended minimum set that would allow the evaluation report to adequately describe and compare client groups and to perform risk adjustment in the analysis of utilisation outcomes. A list of chronic conditions has been compiled using the *OARS* MFAQ physical health scale, Personal Alert Victoria assessment record pro forma, and information obtained through the literature review. Providers would be asked to count the number of conditions on the list that each client is currently affected by. A reasonably comprehensive picture of health status on entry will allow the evaluation to quantify the level of chronic illness among clients and will give perspective to utilisation outcomes in terms of the care continuum model of supplementation and substitution.

Recommended client health status data items are listed below.

**Self- or informant-rated health status of client**

How would you rate your/your care recipient's health at the present time?

[3] Excellent      [2] Good      [1] Fair      [0] Poor      [9] Not answered

How does your/your care recipient's present state of health compare to 12 months ago?

[2] Better      [1] About the same      [0] Worse      [9] Not answered

**Client core activity – level of difficulty**

[The following three items should be rated by a case manager or other health professional who is familiar with the client, according to guidelines in the ACAP, CSTDA and National Community Services data dictionaries. These items will be used to assess each client's level of core activity restriction, consistent with definitions used by the Australian Bureau of Statistics. ]

What level of difficulty does the client currently experience in each of the following life areas? (see rating scale below)

Self-care \_\_\_\_\_

Mobility \_\_\_\_\_

Communication \_\_\_\_\_

*Rating scale*

[0] No difficulty

[3] Severe difficulty

[1] Mild difficulty

[4] Profound difficulty

[2] Moderate difficulty

[9] Not stated or inadequately described

**Client activity and participation – support needs**

A case manager or other health professional who is familiar with the client and his or her circumstances should rate the client's support needs in each activity and participation domain listed in Table 7 using the following scale:

[1] Unable to do or always needs help or supervision in this life area.

[2] Sometimes needs help/supervision in this life area.

[3] Does not need help or supervision in this life area but uses aids and/or equipment.

[4] Does not need help or supervision in this life area and does not use aids and/or equipment.

[5] Not applicable (only for use where the need for support or assistance is due to the person's age, not their disability. See Guide for use for more detail).

[9] Not stated (not for use in primary data collections)



**Recent use of medical services**

About how many times has client seen a doctor during the past six months other than during a stay in hospital? \_\_\_\_\_ times.

How many times in the past six months has client attended a hospital emergency department for treatment? \_\_\_\_\_ times.

How many days in the past six months has client stayed in hospital as an admitted patient? \_\_\_\_\_ days.

How many days in the past six months has client been in, or registered with a rehabilitation facility or clinic? \_\_\_\_\_ days.

**Medications**

Number of different types of medication that client is presently taking \_\_\_\_\_.

**Medical and physical conditions**

Has client been diagnosed with dementia? ..... No/Yes

Does client have total or partial paralysis? ..... No/Yes

Does client have missing or non-functional limbs? ..... No/Yes

Has client sustained a fracture or broken bone in the last three months? ..... No/Yes

Poor eyesight (with contacts or glasses)? ..... No/Yes

Poor hearing (with hearing aid)? ..... No/Yes

Does client have impaired gait or balance leading to near falls? ..... No/Yes

Number of chronic health conditions at the present time (from supplied list)

**Emergencies in the past 12 months**

During the past 12 months, has the client experienced any of the following events?

A fall that resulted in significant injury such as fracture?.... No/Yes

A fall or other incident that rendered him/her immobile or unable to summon assistance for 30 minutes or more?.. No/Yes

Other incident which could be life threatening or associated with a rapid and severe deterioration in health (eg. TIA, cardiac arrest, respiratory distress, trauma)?..... No/Yes

### 3.4 Client social resources profile

The level of social support available to a client is an important determinant of health service utilisation. Measures of social resources should be recorded at entry to the pilot service and on discharge. The client's (or carer's) subjective assessment of access to assistance could be included as a key evaluation outcome measure. It is possible that measures in the social resources domain will change throughout the evaluation period. Carers might become unavailable. New carers might appear with the injection of additional formal support for the family member. Existing carers and clients could develop new confidence and competence from the experience of case management and involvement in care planning.

As a minimum, the client social resources profile will need to record information on the availability, residency status and relationship of a primary carer (at entry and discharge). These items are defined in the National Community Services Data Dictionary. Other key items for the social resources profile include carer outcome measures listed in Table 9. It might also be useful to obtain information on whether there has been a recent change in the availability of informal care eg. death of a spouse, relocation of a secondary carer.

A more comprehensive social resources module could take additional items from a standard social resource scale. For example, the *OARS MFAQ* seeks information on a client's wider social network and frequency of social contacts (Fillenbaum 1988). Hawthorne et al. (1999) showed that scores from this scale were associated with entry to long-term residential care in an Australian setting. This type of information expands on the carer items in the client profile (national data dictionary items) to obtain a clearer picture of the level of informal support available to the client. It taps into both subjective and objective dimensions of social health. The AIHW recommends this or a similar instrument to complement basic carer data items for a comprehensive social resources evaluation.

To summarise, the minimum set of items for on client social resources should include:

- carer data items from the National Community Service Data Dictionary;
- carer burden (Carer Strain Index scores at times  $t_1$  to  $t_n$ ); and
- carer psychological well-being (GHQ-28 at times  $t_1$  to  $t_n$ ).

Additional data on informal network support could be included in the framework if desired, using a standard social resources instrument such as the *OARS MFAQ* social resources scale.

### 3.5 Provider profiles

A service provider evaluation module should be designed to collect information on the service environment (community/residential; on-site medical services etc.), range of services, linkages (ACAT/ACAS, general practitioners, hospitals), financials, case management model, purchaser/provider model and so on. Providers should be

asked to outline the health services context in their local area. This will involve one-off measurement employing site visits and semi-structured interview methods.

The national evaluation framework should provide scope for individual pilot sites to volunteer for *ex post* quasi-experimental or time series-type evaluation of client outcomes if suitable data is available.

### **3.6 Client activities and health events**

A separate evaluation data set should be used to record each service event for a client on a new unit record. These records can be linked to the client profile and client resources profile using a client and provider identification codes. The AIHW has compiled a minimum list of pilot program service types for which utilisation should be measured and costed (Table 11). The framework should specify standard units for recording activity against each type of service.

Costs for the different services will of course vary between providers. Where services are not recorded in dollar units, costs by service type can be recorded in the provider profile and applied uniformly to actual utilisation for each client. Subsidies and client payments can be recorded in the client profile or client service activity profile in the case of payments made for individual service events, noting that some providers will offer special rates for disadvantaged clients. Co-payments for individual services should be recorded against the client service event.

**Table 11: Pilot program service categories**

<b>Service category</b>	<b>Units</b>	<b>Notes</b>
<b>Case management</b>		
Initial in-home assessment	Hours	Case management 2 (One individual has been assigned to coordinate needs assessment and services for this client)
Follow-up assessment and service coordination	Number of contacts	1 (A case manager has been assigned to coordinated needs assessment and services for this client but more than one person will act in this capacity) 0 (No case manager has been assigned to this client)
Medication assessment reviews	Number of reviews	
<b>Medical and allied health services</b>		
General practitioner consultation (EPC)	Number of contacts	
General practitioner consultation (no EPC)	Number of contacts	
Nursing care	Number of contacts	
Physiotherapy	Sessions <sup>(a)</sup>	
Social work	Sessions <sup>(a)</sup>	
Occupational/diversional therapy	Sessions <sup>(a)</sup>	
Podiatry	Sessions <sup>(a)</sup>	
Dietician	Number of referrals	
Psychologist consultation	Sessions <sup>(a)</sup>	
Alternative therapies	Sessions <sup>(a)</sup>	
Other allied health specialty	Sessions <sup>(a)</sup>	Please specify
Geriatrician (including psychogeriatrician)	Number of contacts	
Neurologist	Number of contacts	
Psychiatrist	Number of contacts	
Other medical specialist	Number of contacts	Please specify
<b>Dementia (or memory)-specific health services</b>		
Dementia management service (including memory clinics)	Number of contacts	
Behaviour management service	Number of contacts	
Dementia advisory service including hotline (staff only)	Number of contacts	
<b>Community health services</b>		
Community mental health service	Number of contacts	
Memory clinic	Number of contacts	
Rehabilitation clinic	Number of contacts	

*(continued)*

**Table 11 (continued): Pilot program service categories**

<b>Service category</b>	<b>Units</b>	<b>Notes</b>
<b>In-home assistance</b>		
Personal care services	Sessions <sup>(a)</sup>	
Domestic assistance	Sessions <sup>(a)</sup>	
Delivered meals	Number of meals	
Meal preparation/ food services (other than delivered meals)	Sessions <sup>(a)</sup>	
Linen services	Number of deliveries	
Transport services	Number of one-way trips	
Home maintenance (excluding home modifications)	Dollars	
Social support	Sessions <sup>(a)</sup>	
<b>Other community services</b>		
Employment referral & counselling	Number of contacts	
Day leisure/recreational program	Days	
Financial planning/management	Number of contacts	
Interpreter/translator	Dollars	
Temporary accommodation	Dollars	
Other accommodation assistance services	Dollars	
Other, please specify		
<b>Aids and equipment</b>		
Mobility aids	Dollars	
Vision aids	Dollars	
Hearing aids	Dollars	
Continence aids	Dollars	
Home modifications	Dollars	
Other, please specify		
<b>Carer respite services</b>		
In-home respite	Hours	
Day centre respite	Days	
Residential respite	Days	

*(continued)*

**Table 11 (continued): Pilot program service categories**

Service category	Units	Notes
<b>Other services for carers</b>		
Information and education services	Number of contacts	
Individual counselling and referral services (counselling for client should be recorded as social work)	Number of contacts	
Carer social support networks (focus groups, carer networks etc)	Number of events	Detail of type of service will be recorded against service provider
Dementia advisory service	Number of contacts	
Medical services through pilot program	Number of contacts	
Other, please specify		

Client health events requiring external services that are required for measuring utilisation outcomes will need to be recorded in a separate evaluation data set, the structure of which provides for the minimum level of information that is required for hospital admissions and emergency department attendances (Table 12). The index admission for clients in flow-through pilot programs ie. the admission leading to referral to the service, should be recorded in this data set. Optionally, this data set could record visits to general practitioners and medical specialists for comprehensive outcome evaluation.

**Table 12: Non-pilot program service categories**

Service category	Unit	Notes
<b>Hospital services (admitted patient care)</b>		
Day hospital (other than for psychogeriatric or psychiatric care)	Number of admissions	
Psychiatric unit	Number of admissions, LOS	
Psychogeriatric care unit	Number of contacts	
Overnight hospitalisation	Number of admissions, LOS (dates)	Principal diagnosis, urgency of admission, medical or surgical
Emergency department presentation	Number and dates	
<b>Medical services (outpatient)</b>		
General practitioner	Contacts	
Medical specialist	Contacts	

(a) Standard sessions of 15 minutes duration.

## 4 Project outline and options

### 4.1 Project outline

This part of the report outlines the main phases of the evaluation projects for the dementia and disability services pilots. The project outline presented here identifies the main phases of evaluation activity. Assuming that each evaluation project will conform to a common evaluation framework, the design phase activities will cover the dementia and disability streams. It will be possible to use the same basic reporting structure while also accommodating different emphases in the final evaluation reports if necessary.

The evaluations will involve five main phases: design, preparation and coordination, data supply, analysis and finally, reporting (Table 13). Most of the activities in the design and preparation/coordination phases (apart from test data processing) would be undertaken once if one evaluation and reporting framework is adopted for the three evaluation projects. Then, only the data supply, analysis and reporting phases would be repeated, once for each project.

To cover all pilot sites in the (optional) site visit schedule, we estimate that there would be 15 sites to visit in total (an estimated 9 dementia pilots and 6 disability pilots). The most efficient way to cover all sites might be to plan for two rounds of site visits, with the option of not proceeding with the second if, in the first round, information gathered suggests a sufficiently consistent approach to provider profiling. After a first wave, it is conceivable that the service provider profile instrument would be comprehensive enough to administer via teleconference. Following this logic, the key would be to include all jurisdictions in the first round of site visits, and cover pilot services that target rural and remote communities as well as the metropolitan services.

It is clear that the evaluation project for the dementia stream, including one-off development of the evaluation framework will extend to the end of April 2005 if these milestones are achieved. The time allocated to analysis and reporting is a bare minimum and poses some risk given that these phases fall in late-2004 to early-2005. For the measurement of utilisation outcomes, follow-up will need to occur later – ideally 6 and 12 months – leading to a two-stage evaluation. The project outline that appears in Table 13 should be viewed as the minimum timeframe to complete one evaluation report on intermediate outcomes, taking in a comparative analysis of cost and short-term utilisation outcomes against data from external sources.

**Table 13: Innovative Pool pilot services national evaluation: project phases and activities**

<b>Phase/major activity</b>	<b>Est elapsed time/ completion date</b>	<b>Tasks</b>
<b>Design phase</b>	<b>12 weeks<sup>(a)</sup> 27 February</b>	
Prepare overview of national evaluation framework document	12 December	Document to inform providers of the core assessments and data items that will be required for evaluation purposes and an assessment schedule covering first 3 months of client activity (to cover the period leading up to full framework specification).
AIHW Ethics Committee submission	Deadline for submission 30 January 2004	<ul style="list-style-type: none"> <li>• Prepare and submit application for approval from AIHW ethics committee to proceed with evaluation.</li> <li>• Prepare provider agreement form to allow each provider to verify that data is supplied only for clients who have given written consent to participate in the evaluation.</li> </ul>
Develop national evaluation framework specifications	8 weeks	<ul style="list-style-type: none"> <li>• Produce web-based evaluation manual</li> <li>• Secure permission to use copyright tools</li> <li>• Establish expert reference group</li> <li>• Map required data items to national data dictionary definitions</li> <li>• Devise consistent coding schema for non-standard data items eg. assessment instrument scales</li> <li>• Produce templates for evaluation data sets</li> <li>• Develop guidelines on recording intervals</li> <li>• Produce static web pages containing data specifications, templates and guidelines</li> <li>• Set up web-based evaluation liaison service</li> <li>• Produce pilot site interview schedules</li> </ul>
Site visits	4 weeks (concurrent)	<ul style="list-style-type: none"> <li>• Conduct semi-structured interviews to obtain information on provider profile and service environment</li> <li>• Discuss the evaluation data requirements</li> <li>• Discuss possible arrangements for conducting post-discharge client follow-up</li> <li>• Consult with early-start providers who might need to deviate from the evaluation framework</li> </ul>
<b>Preparation and coordination</b>	<b>26 weeks<sup>(a)</sup> 27 August 2004</b>	
Provider liaison	Ongoing	Respond to questions to do with data definitions via e-mail and phone.
Issue data supply schedule	2 weeks	<ul style="list-style-type: none"> <li>• Devise a schedule for providers to supply interim data for completeness and validity checking. Issue schedule to providers</li> <li>• Liaise with providers on capacity to meet schedule and anticipated volume of data</li> </ul>
Develop data validation tools	8 weeks	Produce programs to automate field validation and cross-checks of data items.

*(continued)*



**Table 13 (continued): Innovative Pool pilot services national evaluation: project phases and activities**

<b>Phase/major activity</b>	<b>Est elapsed time/ completion date</b>	<b>Tasks</b>
Plan structure of evaluation report	4 weeks	<ul style="list-style-type: none"> <li>Chapter outlines</li> <li>Data analysis plan (specify table and graph outlines)</li> <li>Refer plan to external reference group for comment</li> </ul>
Collate external data for use in comparative analysis	4 weeks	<ul style="list-style-type: none"> <li>Obtain appropriate external comparative data sets</li> <li>Produce extracts or process to produce benchmark outcomes</li> <li>Refer to external reference group for comment</li> </ul>
Develop & pilot satisfaction survey instruments	6 weeks	<ul style="list-style-type: none"> <li>Prepare a client/carer satisfaction survey</li> <li>Prepare a service provider experience feedback form</li> <li>Forms production</li> <li>Devise survey administration strategy</li> </ul>
Test data load and validation	4 weeks	<ul style="list-style-type: none"> <li>Receive and process test data sets from pilot sites</li> <li>Liaise with pilots on data quality and completeness</li> </ul>
<b>Data supply phase</b>	<b>8 weeks<sup>(a)</sup> 22 October 2004</b>	
Production data load	4 weeks	<ul style="list-style-type: none"> <li>Load first supply of final data, validate and provide feedback</li> <li>If necessary, load second supply and perform data cleaning</li> </ul>
Survey administration	8 weeks	<ul style="list-style-type: none"> <li>Administer client surveys/follow-up</li> <li>Data entry and validation</li> </ul>
<b>Analysis phase</b>	<b>8 weeks<sup>(a)(b)</sup> 17 December 2004</b>	Produce tables and graphs for final report according to specifications
<b>Reporting phase</b>	<b>12 weeks<sup>(a)</sup> End-April 2005</b>	<ul style="list-style-type: none"> <li>Produce preliminary evaluation report</li> <li>Seek referee comments</li> <li>Finalise content</li> <li>Report production</li> <li>Acceptance</li> </ul>

(a) Elapsed time of activities may not sum to time allocated to project phase because some activities will be undertaken concurrently. Estimates are based on a project team of 2 dedicated staff for the duration in addition to AIHW corporate support plus additional staff resources for period covering site visits.

(b) 8 weeks is the minimum time to analyse pilot services data including a comparative analysis against external utilisation and cost data. This period would need to be extended if the evaluation is to include detailed analysis of before and after service utilisation at client level (a separate evaluation option).

## 4.2 Evaluation options

This section outlines a number of options that will dictate the level of detailed analysis available for the final reports. Apart from site visits, the options are primarily distinguished by what would be covered in the data supply, analysis and reporting phases of each project.

In devising options for the evaluation projects, the AIHW has made a number of assumptions:

1. Service providers will have obtained client consent to participate in the evaluation as part of their Client Agreement. The AIHW, if appointed for the evaluation, would seek written confirmation from each provider that all confidentialised client data supplied to for evaluation purposes is subject to a current Client Agreement with that provider.
2. Data supplied for evaluation will comply with specifications in the national evaluation framework. For the purpose of data quality assurance, the evaluation team would encourage providers to supply test data during the preparation and coordination phase of the project. The team could then liaise with providers to address any obvious problems well in advance of production data supply. The project plan also factors in an amount of time to follow-up on data problems in the final load. Unreasonable delays in the analysis and reporting milestones should not be jeopardised by late supply of evaluation data from individual sites.
3. It is assumed that the evaluation team would not be required to assist service providers with data base development and data entry, apart from producing templates and guidelines on the evaluation web site. Evaluation reference material will specify acceptable software packages for data submission. The evaluation team would reserve the right to reject evaluation data sets from a provider if they are found to be unsuitable for the planned analysis.
4. Evaluation options described here cover all providers that supply data which complies with the requirements of the national framework. Some early-start providers will have established assessment protocols and systems. Parallel running of existing system procedures and procedures required for the national evaluation could prove problematic for these providers. It would be possible to report on a case-by-case basis, however this is not included in the options presented here.

Given a consistent national evaluation framework that is in place following the project design phase, the preparation/coordination, analysis and reporting phases of each project could aim to achieve one of three options:

- a basic evaluation including comparative evaluation against external data sources;
- a basic evaluation with full provider profiling;
- a comprehensive evaluation that includes client-level before and after service utilisation and cost analysis for selected sites.

### *Comparative evaluation*

Outcome measures and instruments have been recommended with two types of comparative evaluation in mind. The scope of measurement proposed here is designed to facilitate the comparison of pilot services client profiles (sociodemographic and disability profiles) with population and program data. This type of profile comparison provides contextual information to an evaluation and can assist in the redesign or development of service delivery programs. It does not contribute to an impact evaluation of health or utilisation outcomes. For example, Aged Care Assessment Program (ACAP) data held by ACAP Evaluation Units would facilitate a comparison of the disability and living arrangement profile of Innovative Pool clients with the wider population of people who have been assessed, but would not provide before and after measurements for impact evaluation.

A second level of evaluation aims to attribute outcomes to interventions. In its simplest form, individual pilot sites would volunteer to participate in more detailed client-level evaluation, drawing on client historical data. This level of analysis would be based on the care continuum model of risk adjustment. It does not involve control or comparison groups, and as such, is still a primarily observational approach. While avoiding selection bias, a single group time series-type evaluation is vulnerable to the effects of maturation and regression towards the mean in conventional study settings. These issues may pose less of a threat in real terms given the target populations and eligibility criteria of Innovative Pool: clients referred to pilot services are known to be at risk of premature or avoidable entry to residential aged care by virtue of their aged care assessment recommendation. The value of historical client data in this type of evaluation should not be underestimated and the providers that are able and willing to assist in this type of evaluation might be identified in early site visits.

The attribution of health and utilisation outcomes to interventions would require at least a partial coverage *ex post* quasi-experimental research design. For the attribution of health outcomes, the same outcome measures need to be available for both the pilot services clients and an equivalent comparison group. The most likely source of usable health outcome data for impact evaluation purposes is individual service providers. Impact evaluation of utilisation outcomes will require client follow-up. Depending on the follow-up period, it might be possible to source comparative utilisation outcomes from other studies and, possibly, national program data. Sources of such comparative data for the older 'at risk' population requires a detailed investigation. It may be possible to draw on the results of some of the Australian Coordinated Care Trials (CCT), all of which were required to record ACAT assessment as a source of referral. Some of the CCT geographic control groups might correspond to Innovative Pool pilot site catchment areas. CCT randomised control groups could be used to calculate benchmark rates by jurisdiction. It is unknown what proportion of CCT clients were referred by an ACAT. Selection bias and history effects are the main threats to the validity of an impact evaluation that uses external sources of data for controls. If the eligibility criteria cannot be

replicated the evaluation has low internal validity. To minimise these threats it would be necessary to establish recent or prospective ACAT client control groups. The extent to which detailed within-subject analysis or impact evaluation based on equivalent comparison groups is undertaken will depend on cost, other practical issues, and the extent to which threats to internal validity can be minimised. The AIHW has flagged the possibility of establishing wait list controls for an evaluation of utilisation outcomes, however, such a strategy requires further consultation and would need to be approved by a Human Research Ethics Committee. The evaluation framework should therefore be designed to allow for impact evaluation on a local level without being overly prescriptive.

Inclusions for each option of the first-stage evaluation period are listed below.

## **Basic evaluation**

### *Inclusions*

1. Coordination of supply, validation and analysis of all core data items specified in the evaluation framework.
2. Final evaluation report to include:
  - Client population and provider profiles.
  - Client and carer health outcome measures.
  - Patterns of service utilisation and cost.
  - Comparative evaluation of health service utilisation and client population disability profiles using external data sources where possible (eg. results from the Australian Coordinated Care Trials, ABS Survey of Disability Ageing and Carers, Aged Care Assessment Program data and/or Aged Care Management Information System).
  - Evaluation of cost outcomes compared with CACP, EACH, RAC data.
3. Maintenance of the web-based evaluation reference manual.
4. Liaison with service provider evaluation contact officers – providers will be able to refer to the evaluation web-site for data specifications and guidelines and can refer to the AIHW project team for clarification of any data issues that arise via e-mail or telephone
5. Consultation with an expert reference group on analysis and reporting (if applicable).
6. Progress meetings with the Department.

### *Exclusions*

1. Site visits.
2. Analysis of patterns of before and after health service utilisation using client-level data.
3. Evaluation of sites whose client assessments do not conform to the national framework.

## **Basic evaluation plus site visits**

### *Inclusions*

1. Basic evaluation inclusions.
2. Scheduled site visits.

Site visits in early-2004 by AIHW project officer and a senior health/aged care services consultant. The purpose of these visits would be to establish rapport with providers, build a comprehensive profile of the service environment (catchment population profile, sources of referral, ongoing services, staffing arrangements, local and state government programs) and work through ways for early-start providers to incorporate the recently introduced framework. Visits would also help to identify conditions peculiar to each provider that might impact on the interpretation of results.

### *Exclusions*

1. Analysis of patterns of before and after health service utilisation using client-level data.
2. Evaluation of sites whose client assessments do not conform to the national framework.

Site visits would make available more detailed information on service providers and their clientele than is possible to obtain through questionnaires. A less expensive but less effective approach would be to meet with service providers via teleconference. One of the benefits of a site visit is the capacity to assess sites for participation in detailed client-level evaluation (see 3.2.3). In an interview situation, providers are able to demonstrate on-line data systems. More direct involvement through could also help to uncover sources of local data for comparative evaluation. Finally, effective site visits can motivate providers to actively participate in evaluation activity rather than regard it as an administrative burden. This has benefits in terms of data quality and project management.

## **Comprehensive (continuum of care model) evaluation.**

### *Inclusions*

1. Basic evaluation inclusions plus scheduled site visits.
2. Collection of 12-month historical MBS (if possible) and hospital service utilisation data for clients at selected sites.
3. Detailed analysis and reporting of client-level health and participation outcome trajectories using a continuum of care model based on client assessment for known risk factors.
4. Comparison of historical and post-intervention service utilisation (MBS and hospital morbidity data if possible).

### *Exclusions*

1. Evaluation of sites whose client assessments do not conform to the national framework.

### **4.3 Expert reference group**

The AIHW recommends that the evaluation project team has access to a small group of subject matter experts in the fields of dementia care, disability services, post-acute care, community care, carers and cultural diversity for advice during the design, implementation and reporting phases.

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