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**Family &
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Ageing, Disability & Home Care

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Key Findings

The particular focus of this report is shaped by lessons from projects related to outcome measurement conducted by one research centre over a decade and the policy context of the current (late 2010) reform agenda in both the health and community care sectors. These sectors are not separate systems when looked at from the point of view of an individual who requires assistance to maintain their health and independence at home and lessons from both sectors are useful. Common and/or better integrated systems that are adapted to accommodate more of the client's own viewpoint (as distinct from a program management point of view) will support the policy aim of personalising or individualising service responses.

The policy aim of personalising service provision implies a systemic capacity for understanding the full range of a person's needs, as well as their goals in seeking a particular form of assistance. The service system, from the point of initial assessment through to the review of care plans and case closure, should then be able to better organise and provide a range of more individualized responses to meeting their identified needs. This addresses the concern that separate programs assess for, and offer, only those services for which people are eligible. And it recognises that eligibility is not the same as need.

Improving the capacity for outcome measurement in community care is one technical component that responds to these policy aims. The response starts with better organised assessment information at the intake point that includes the client's goals. More standardised information collected in the initial and ongoing processes of assessment can form part of a continuous client record inside client information systems. If the same data elements are collected at different points, then the 'change scores' can be used for the purposes of measuring the outcomes of services or interventions.

Some client characteristics are more useful than others for the purposes of measuring outcomes. The planned introduction of routine and standardised measurement of functional abilities constituted an important first step on a longer development pathway leading to a system for outcome measurement in community care programs. The physical and mental abilities that everyone needs to live independently predicts who will need community care and/or more active service models like rehabilitation and also how much that care will cost. And the personal and social context of those abilities also needs to be understood. So information on carer status, care network sustainability, social isolation and/or other factors useful for measuring well-being, can be standardised and routinely collected and used to understand the outcomes achieved over time. It is possible to use that information to both measure individual client need and also inform program-level and resource allocation decisions.

The synthesis of our findings suggests it is possible to build and support a system that can routinely capture a manageable set of key indicators that can help to plan and deliver individual care and provide a good picture of how well the service system is doing, not only how many services of different types are provided. The preconditions are the design of client information systems around the goal of care and an agreed classification of clients based on need that can act as a "common currency" between providers, funders and other stakeholders, and that can be refined over time based on analysing routinely collected data.

One question that still needs to be asked and answered is how to build a data repository function to support a stable longer term work program. This may not be just one information system but could be brought together from many information systems that follow agreed standards so that summary information from a wide number of service providers in a distributed network could be combined in order to make judgments about outcomes. Central direction will still be needed so that each new generation of a system should progressively include more useful variables for classification and outcome measurement purposes.

Executive Summary

The issues in measuring outcomes in community care can be characterised as being complex and technical, but addressing them is feasible if it is recognised that a number of key building blocks are already well known and if a longer term perspective on the issues is adopted.

So as to be able to consolidate a disparate number of projects completed at different times and different policy and program contexts, this research project summarises lessons from a series of previous projects in community care assessment systems that are linked to the requirements for systematic outcome measurement. The focus is primarily on improving the means for measuring outcomes and the information management and sector development issues. The evidence we used is one research centre's work that has included reviews of current literature and evidence, as well as field trials of intake and assessment systems, priority rating models, evaluations of community interventions and client classification models.

The shift to an outcomes focus

Collecting information and reporting on that information in a way that starts with people's quality of life is not the same as measuring the quality and quantity of the services being provided to them. In the international and national context, measuring the quality of care and using those measurements to promote improvements in service delivery, to influence payment for services, and to increase transparency are now relatively commonplace in the health sector and are increasingly evident in community care.

Functional independence has been signalled as the key concept in broadening the focus of community care to include providing services in ways that maintain and promote independence, as well as helping to avoid premature or inappropriate admission to long term residential care. From discussions with community-based agencies it is clear that many are developing their own programs that rely on quality measurement and reporting.

This shift of focus involves agencies adopting systems for more rigorous and evidence-based service development, shown in annual consumer surveys and better ways of planning care. At the program level it implies a shift to the contracting and monitoring of services around a better understanding of user needs. This can supplement, and may eventually replace, the requirements to report output and input-based performance indicators to program managers. It implies more focused activity in the near future to develop and use indicators and processes defined and developed specifically to help understand how well services are contributing to the outcomes users want to see.

In practice this means more carefully selected and standardised data elements capable of being routinely collected at the client level. The principle is to collect the right combination of these data elements relevant to the goal of care at the start and end of an 'episode of community care' so that any changes associated with the goal for a particular client can be measured. How the 'change scores' are interpreted depends very much on the goal of the service or intervention being provided for that particular client.

Although more complex, the processes of measuring outcomes in community care can build on the logic that has been developed in related systems, in particular in rehabilitation and in palliative care. The 'goal of care' is the key concept that leads to a meaningful classification of clients and the definition of 'episodes' and suitable data elements that collect the right client characteristics. From examples of current good practice these standardised data elements can be used by data repositories where analyses and 'data-driven solutions' can be used to guide a long term data development program. That is why addressing the complexity of the issues in measuring outcomes in community is both feasible and necessary.

What we already know

Measuring outcomes in community care can start from an existing evidence base. We know that in community care and for people with protracted and chronic illnesses or conditions that last a life time, measuring outcomes is more complex than in short term health-related interventions. The overall results of a hospital stay or for a period of time in residential care can be looked at if there are suitable codes and classifications. There is a lot more variability involved in community care, where outcomes may be related to whether there is a carer or not, what other services are being used, or what the person's living arrangements are.

We already know that outcomes assessment, by definition, can't be a one-off event. It requires a concept of an 'episode'. In acute health care the episode is the whole time a patient is in hospital from admission to discharge. In residential care the unit of counting is also straightforward when activity is counted per day. An episode of community care is more likely to be defined in terms a pre-set time period for review, and that implies re-assessment rules. These would be based on a protocol, and criteria for when an episode starts and ends, such as pre-agreed time periods (e.g., each 90 days) or some form of natural 'bookends' (e.g. at logical transition points) such as when a care plan or individual service plan is reviewed. Or an episode might be marked by a point of transition such as when a package of care and support ends, or when a client's or carer's needs change.

Previous pilots and trials and existing systems have tested key indicators for outcome measurement including the level of a client's functional dependency, their carer status, their care network's sustainability, indicators of social isolation and/or other factors useful for measuring well-being. We also know that these indicators can be standardised and used to track the client's 'change scores' over time, although this is rarely done in community settings. It is even under-developed in relatively well defined fields like ambulatory rehabilitation and community palliative care, where most of the work of this nature has been done in Australia.

The nine-item HACC functional screen is a good example of data elements already in place that operationalises the concept of functional independence, is routinely collected at the client level in the HACC MDS and works as a core set of items with multiple uses if combined with data from other domains. Although developed for use mainly with the frail aged, the functional hierarchy has proved to be also useful with young people with disabilities in Post School Programs, as well as a key component in priority rating systems in community care and in specific applications such as the NSW Home Care Functional Screening Tool where it is also used in aggregate at the program level to make comparisons across service settings.

However a functional screen is just that – a screen – and as such it is intended to act as a pathway into other levels of assessment. It is insufficient in its level of detail to be an assessment that is used at the level of planning care and for specifying service levels. For example in personal care and domestic assistance, an ability to break down a global goal of improving independence into service-specific tasks like bathing, grooming, meal preparation, transport to a day centre and so on, is more useful. So outcome measures will also need to include more detail and specific tools to measure characteristics like social and emotional well being and social isolation.

Outcomes have to be linked to the goal of the intervention and the goal of care is known to be useful as the first branch in a system for client classification. No change, or an arrest in the rate of decline, can be a good outcome in some cases. In the Australian Community Care Needs Assessment (ACCNA) trial the ACCNA goals of care were to:

- (1) Improve current level of function and independence after a recent acute illness/event
- (2) Improve current level of function and independence (other)
- (3) Maintain current level of function and independence
- (4) Reduce rate of decline in level of function and independence

The model for care planning used in the COAG-funded Illawarra Coordinated Care Trial was more complex because it was wider in scope than the HACC program. It showed how 30 client classes could cover complex needs and support a broader range of models of care as well as how they can be funded. That model included useful definitions levels of case management from complex planning to more straightforward navigation support.

Priority rating for the Program of Aids for Disabled People (PADP) using need and capacity to benefit, and the combinations of data elements (derived data items) in the Ongoing Needs Identification (ONI) intake assessment module show how initial screening tools might be flexibly adapted to a range of functions in different programs. For example the data collected in the ACCNA field trial suggested that further refinement of an index of rehabilitation potential would be feasible. The Post School Programs classification is used to predict the best placement for young people leaving school but because the assessment is only used as a one-off event and does not become part of an ongoing electronic record, the ability to test if the person benefited from the allocation decisions that were made or in fact went to the right program, is not possible.

Implications for a longer and systematic work program

These examples show how priority rating and classification systems based on a common 'data element pool' are feasible. They show how the right information can be made more useful by being applied at different points in time. But making further progress in the direction of outcome measurement requires a continuous electronic record and more continuity in the approach used across different programs. These issues could be resolved over time as part of a longer-term research and development agenda based on data analysis.

The exploratory study has made a case for outcome measurement being reliant on better ways to classify clients, based on their goal of care and the main characteristics that drive their need for care and support. The recommended ways of adopting a more systematic approach can start with initial agreement on a common interest in, and shared understanding of the value of adopting what we have called a 'common outcomes-oriented classification' approach.

A program should be developed to build a system over time that assesses consistently and equitably, independently of service provision, and facilitates the purchase of services the person needs, with case manager and brokerage if necessary. The data elements in Appendix 2 of the full report, along with recommended items on other measures such as social isolation, could be incorporated in CIS 2 to form Version 1 of a Core Community Care Data Item Pool for supporting information sharing across programs, service types and agencies. Most of the listed items are already in place as a result of previous work in these areas.

The wider context

The COAG reforms require a continuous electronic record, standardised and more consistent methods of assessing needs, agreed ways of classifying service users and routinely useful data systems for measuring the outcomes of service provision. Systems for measuring effectiveness imply the primacy of outcomes-based thinking about what care and support is received, and how it is experienced by the user can then be used as an indicator of quality. A recent Productivity Commission report on the not-for-profit sector recommended (R.5.4) that a focus of research be supported within a framework designed for improving community care effectiveness.

Promoting community care and support services that actually make a measurable difference for carers and consumers needs to be supported by an information management system that detects those measurable differences. While it is a complex undertaking, and the timelines involved in building sustainable quality improvement systems are long, there is evidence that workable systems can be built to be useful to clients, providers and managers, using rigorous and practical methods that can support them to collect the right data.

1 Introduction to the Full Report

The community care sector is inherently complicated and produces a complex array of outcomes. The sector is also at the interface between the acute care, residential and community aged care, disability and housing sectors and requires ways of relating its work to activities in at least some of those other sectors.

This report is an exploratory study of outcome measurement in community care. It describes what is known about this field of research and practice (in mid 2010). It is based on three primary sources of evidence: detailed lessons from the review of a series of linked studies by one research group (the Centre for Health Service Development, University of Wollongong – CHSD); findings from a wider review of current practice and national reforms; and targeted interviews on measuring outcomes with selected providers, clients and carers.

There are useful distinctions and clarifications that are made throughout this report. The definition of ‘*outcome*’ in the glossary in the last Appendix refers to both a *time* element and the *level* at which outcomes might be achieved. So interventions may have short, medium and long term impacts, and when outcome measures are used in evaluation studies it is logical to distinguish between the client (and carer) level, provider (agency or organisational) level and system (or program) levels. Useful outcome measurement can occur at any or all of these levels. This three-level framework is useful for summarising the overall findings of this report, and is presented in Section 8.

The measurement focus at the first level of ‘client-centred’ outcomes has been shaped by evidence from research primarily focused on health-related outcomes where the methods used can be more rigorous than generally expected in community care. Methodological rigour is more possible because of the more controlled settings in hospitals or specialist clinics, the use of clearly defined and time-limited interventions, and the organisational, academic and clinical resources that are more likely to be used to gather reliable data and make evaluation findings that relevant to policies and programs. In practical terms the health system has a tier of support and the technical tools for coding and classifying client-level information and in some cases (described in Section 4) for analysing and reporting on data from clinical encounters.

Improvements in a patient’s health status can be measured against specific *goals* of a health intervention or the expected outcomes that are linked to their diagnosis. Where diagnosis is a less significant factor, for example in sub-acute or non-acute care such as rehabilitation and palliative care, outcome measurement can still be rigorous when, for example, they are based on functional assessment scores, or quality of life indicators such as pain or symptom severity scores.

Community care services on the other hand have goals that are generally broader than in the health sector and because of the aims of the programs that are delivered; they are primarily linked to the maintenance of independence in a home environment. A range of different service types have been designed to assist in maintaining or improving a client’s functional abilities in tasks of daily living, such as domestic and self-care tasks, mobility, transport, shopping and social participation. It is rarely clear which of these service types will have made a difference for a client or carer because it is intended that services have their own specific goals as well as working together towards the more general goal of maintaining independence.

This ‘independence’ goal of community care has been evolving in the past decade and can vary from maintenance by providing low levels of basic domestic services, to more active and intensive interventions with restorative goals, through to prevention framed as ‘wellness’ and ‘enablement’ goals. The 2007 Review of the HACC Program has signalled this broadening in focus to include providing services in ways that maintain and promote independence, as well as helping to avoid premature or inappropriate admission to long term residential care.

This more active and restorative focus highlights the importance of measures of functional ability as core outcome measures. While functional measures are core and common to a range of service types, the evidence from the literature and current service practice emphasises the value of measuring other outcome domains such as social and emotional well-being, quality of life, health conditions and behaviours, and the client's experience of the 'processes' in the care they receive, such as qualities like personal control, respect and continuity.

At the agency and organisational level, the routine measurement of outcomes is possible by aggregating and comparing data on client and carer-level outcomes. Agency-level outcomes do not get replaced by a client-focussed outcomes approach, but they can supplement other measures like workforce competencies and turn-over, availability of services and periodic measures of user satisfaction, for example in agencies' Annual Reports.

Given these complexities, the aim of a client outcomes focus is to ensure that particular meaningful *comparisons* are possible for the purposes of maintaining quality and for service development, for example:

- a capacity to compare aggregated person-level outcome measures *within* an organisation can answer questions at the agency level about the *relative effectiveness of different service responses*;
- a capacity to compare common data *across* agencies for benchmarking purposes can answer questions at the system level about the *relative effectiveness of agencies* and the way they provide their services.

Both of these types of comparisons are consistent with policies of 'transparency' for consumers by way of public reporting on the achievements of agencies. The evidence and experiences from outcome measurement and benchmarking in areas like rehabilitation and palliative care, show it is feasible to move towards more sophisticated approaches in community care without having to continuously and expensively 're-invent the wheel'.

However, in community care there are many good examples of relevant work in evaluations, pilots and reviews, and a wealth of knowledge that exists in the field, relatively little systematic and centrally-guided research and development has taken place.

The aim of the current project is to propose ways to systematically remedy that research and development shortfall over time by strengthening the evidence base and drawing attention to some of the most useful detail. The review of the lessons from projects on assessment system design, pilots, classification and evaluation projects from 1999 to 2010, highlights examples of the building blocks for outcome measurement – using functional ability measures and domains beyond function to create a data item pool that can be used within client information systems to capture the measures most relevant to a particular client or carer's circumstances. The question of what to do next is addressed by a proposed development pathway consistent with the directions proposed by recent national reform decisions.

When outcome measures are more standardised and their collection more routinised, then it is possible to make the transition from mainly counting occasions of service, outputs and processes, to better understanding the impact of those services on clients and carers. The development pathway proposes doing this in an incremental way because building systems of client and carer outcome measurement that are ongoing and sustainable and useful to providers takes a long time. This work in rehabilitation has taken 15 years and in palliative care about 5 years, and based on evidence from the UK in community care, it is reasonable to expect significant progress can be made in NSW and nationally over the five year timescale that has been foreshadowed in the various national reform initiatives.

2 Methods

The stages used in preparing this report were not strictly sequential but follow a logical process where Stage 1 involved the review and synthesis of previous projects completed within one Centre that were relevant to the measurement of client outcomes within the programs administered by the ADHC. The projects were diverse in their aims and in their particular foci, and this diversity poses challenges when the object is to produce a synthesis of the different findings.

Stage 2 explored the issues in moving from services and their outputs and processes to outcomes. The scope here was expanded beyond one Centre's work to include other projects undertaken in the sector and published in both the academic and practice literature. Outcome measures and associated classifications are relatively well established for health system episodes, but far less progress has been made in other care settings. In many cases the administrative resources, relevant datasets and associated codes and classifications required for outcome measurement, are not in place.

Stage 3 investigated what agencies, care recipients and carers think will work for them, based on a validation exercise with NSW agencies who agreed to participate with the exploratory study. This stage used interviews and investigation in the field about how to measure consumer outcomes in routine practice. Stage 3 was not a survey of the field and the agencies were chosen to participate in the research on the basis of agreements reached before the research started and all have a history of innovative practices, concurrent relevant research interests and a willingness to explore the issues of client level outcome measurement in some depth.

The aim of Stage 3 was to test the ideas from the previous stages to assist in developing a realistic strategy to move towards a more consistent approach to measuring outcomes for care recipients and their carers. The understanding what agencies, care recipients and carers think will work for them was based on the review of literature and best practice and a local validation of those findings was thought to be critical in the appraisal of the practicality of any new approach.

Stage 4 was ongoing throughout the project as a review of the current national context was also relevant to the appraisal of the potential for any new approach in NSW. This stage covered the current Commonwealth reform proposals as well as the relevant developments in other states and territories in measuring needs, sharing and using community care information and broadening the scope of assessment systems so as to avoid duplication and inefficiencies.

In practical terms the range of methods that were covered in the exploratory included documentary and policy analysis, quantitative and qualitative material on measuring client characteristics in community care, focussing on existing measurement tools and needs assessment systems. The material reviewed included service development strategies and outcome assessment processes that are currently in operation.

All these issues, but particularly the issue of the diversity of the sector and its approaches, meant the exploratory study was mainly concerned with synthesising lessons from a wide variety of sources. To deal with this challenge, we adapted methods developed for systematic reviews and specifically those for the synthesis of material generated from different sources and research approaches (Parker et al. 2009).

The aim was to 'triangulate' our conclusions from the exploratory study against previous NSW and national experience, lessons from the published and practice literature, discussions with innovative providers and a small number of their clients, and to place the findings in the current national reform context. This has allowed us to synthesise the findings as a model for measuring outcomes in community care settings that includes a set of recommended data items that is capable of being routinely collected according to the circumstances and needs of service users.

3 Review of findings and lessons from previous projects

This section draws out the key messages from a series of projects that are linked by having been carried out by one research centre (CHSD) with funding and involvement from one department (ADHC). The key messages for developing a program of outcome measurement are summarised and each project is described in more detail in Appendix 1 where this body of research material is reviewed in more detail.

3.1 1999 Developing a Classification of Community Care and Support Services' Consumers in NSW (ADD and NSW Health)

This project was commissioned to describe the principles of classification and how they are relevant to the community care sector. It included a review of current practice at the time and proposed a development pathway where the aim was to clarify the concepts involved. It explained how routine client data could be collected at initial assessment and at transition points where re-assessment is conducted. This process for collecting standardised data at different points in time gives change scores that form the basis for measuring the effects of programs.

A community care classification was defined as a classification system that grouped clients into mutually exclusive classes based on their need for services. That is, every client should fit into one and only one class although, over time, a client could move from one class to another. Clients who have similar needs should be in the one group and clients who have different needs should be in different groups. The focus on a broad array of client groups, rather than a more narrow program-dominated approach anticipated the current national reform context by covering community health, aged and disability clients.

3.2 1999-2000 National Dependency Data Items (HACC Functional Screen)

This national project's aim was to design tools to be routinely used to capture the functional status of the HACC population as a first step in measuring consumer needs and relating those needs to resource use. The need for these tools had been highlighted for nearly a decade through numerous reports. However, while functional capacity is of critical importance in driving the need for HACC services, it is not the only measure of need or the only client-related cost driver.

The 9 items in the screen represent a 'functional hierarchy' which are designed to cover the domains of self care, domestic functioning, cognition and behaviour and to prompt more detailed functional assessments that are required to plan the details of providing care. Subsequent developments have demonstrated how the screen forms part of a modular system and how it can be used to determine a priority rating and predict capacity to benefit.

The routine collection of these items in the national HACC Minimum Data Set provides the basis for a relatively simple and practical outcome measurement system if the scores can be compared at different points in time. They also form the starting point for the development of a comprehensive client classification system for the HACC program.

3.3 Coordinated Care Trial Evaluation (CCT)

This evaluation was part of the Council of Australian Governments (COAG) reform agenda in the late 1990s and was one of two trials in NSW covering health and community aged care in the Illawarra and in Hornsby-Kuring-gai. The trial was essentially about a case management approach and demonstrated that the assessment tools used were predictive of outcomes. When all the variables were fitted together, only two were significant (cognitive and instrumental functioning). Just two assessment tools (physical motor and social function) produced a model that accounted for almost as much of the cost of care as the model including all assessment

variables. The refined CCT model of care, developed in the planning of the proposed second round of the trials, was designed for defining consumer needs in terms of a classification approach, and that classification was linked to community care interventions and care packages (see Appendix 3: Illustrations of models from a range of CHSD projects – Recommended consumer classes for the Illawarra Coordinated Care Trial Care Packages). The groups of client classes were based on the goal of care.

3.4 NSW Home Care Priority Rating

The NSW Home Care Service (HCS) implemented the nationally mandated HACC dependency data items in the HCS Referral and Assessment Centres (RACs). By commissioning the CHSD to use a data-driven approach, the HCS developed a priority rating system based on the Functional Screening Tool (FST) that is appropriate to HCS clients.

The project used existing HCS data plus the HACC functional screen items to develop a working model that was gradually refined using routine data. The model enabled the automatic calculation of a priority category and prompts for functional assessments required for each screen to be available in real time. This option provides a transparent and objective tool based on classification principles to manage capacity in a high demand agency. This form of classification enables comparisons to be made across branches on the basis of the dependency levels and relative risks of the clients who are being assessed for services.

3.5 State-based Assessment System Design Projects (2002-2006)

A series of linked projects in NSW, Victoria, South Australia and Queensland were carried out on assessment system design in community care, particularly aimed at standardising intake assessment using the Ongoing Needs Identification (ONI) tools and in Victoria the Service Coordination Tool Templates (SCTT). The design features of a larger system were able to be carried forward and further refined and field tested. For example the work on priority rating for NSW Home Care, because it was data-driven, was able to be used as the foundation for the priority rating system built into the Queensland ONI as it was being implemented State-wide. Considerable investments in training and regional support systems were made in both Victoria and Queensland to back-up the introduction of the new assessment tools, including an on-line and CD ROM versions of a self-directed learning package.

Because of the level of support available, the NSW Community Options Program routinely used the ONI in its contracts with NSW Health to support hospital discharges and other related packaged care and care planning demonstrations, such as the Sub-Acute Fast Track Elderly (SAFTE) pilot (see Section 3.9 below). These different uses were facilitated by building the ONI modules and items into client information systems such as The Care Manager.

The Victorian Service Coordination Tool Templates have had a consistent development and re-development pathway, so there is potential for incorporating a stronger outcomes focus within that pathway. The current cycle of revision of the SCTT, known as the SCTT 2012 revision process, has commenced. It confirms the value of having a common and broad approach with new templates and items for carer's information, palliative care, social networks, chronic disease and complex conditions, people with intellectual disabilities, Aboriginal and Torres Strait Islander consumers, and new validated screening questions for problem gambling and alcohol consumption.

Training has been provided in Victoria and Queensland through a train-the-trainer model. Victoria has also developed what it calls 'implementation products' for vendors of client management software applications including functional specifications, a data dictionary and data model, HL7 messaging standards, and decision support.

3.6 National ACCNA and CENA trials for the Way Forward (2005-2008)

These projects developed Version 1 of the Australian Community Care Needs Assessment (ACCNA) and the Carer Eligibility and Needs Assessment (CENA) instruments. A four level national field trial of both tools was conducted in 2006 where the acceptability and useability of the data elements were confirmed, leading to a series of recommended next steps to resolve technical issues involved in their further development.

The tools were designed for electronic systems, additional fields were added to the functional screen to ask about 'who helps' and the degree to which needs are currently being met. This useful addition is a way to measure unmet need. Relationships between rehabilitation potential, function and other factors were able to be explored to a limited extent within the data collected. A set of clear relationships were found in the data where clients were identified by the assessor as likely to benefit from rehabilitation or what is currently being called a re-ablement or wellness approach, so that a referral for a rehabilitation assessment could be confidently recommended. Subsequent assessment on the same items would be a practical way to assess the outcomes from these more active interventions.

A more complex classification approach to outcome measurement, using the goals in the ACCNA, can be developed as a result of the assessor recording the primary area where assistance is required. The ACCNA design needed further work by analysing a larger set of routine data as a set of step towards routine outcome measurement in community care.

3.7 NSW PADP Priority Rating and Capacity to Benefit (Aids and Appliances)

The purpose of the research was to propose a common state-wide approach to the assessment of applicants for PADP aids and equipment using standardised data elements and a priority rating system. The basis for developing a common person-centred assessment system for applications was the use of 'need' and 'capacity to benefit'.

'Need' was captured with a global measure of function, but function on its own was recognised as being insufficient and functional capabilities can vary over time. The design recognised this in developing more standardised ways of capturing the *context* of the application, and criteria for identifying people potentially disadvantaged by such an approach such as those with life limiting conditions or advanced age.

The recommended tool allowed for the writing of narrative reports, which provide the necessary context for applications both for prescribers and PADP committees. The results showed the importance of first implementing a common assessment system using standard data elements, and then allowing it to operate for a reasonable period of time (one year was recommended) to allow the issues of priority rating based on capacity to benefit to be addressed empirically, using the considerable amount of data that can be collected, especially data from re-assessments so that changes over time could be tracked and the benefits of providing the equipment could be considered.

3.8 Post School Programs allocation model (2002-2010)

DADHC commissioned the Commonwealth Rehabilitation Service (CRS) in 2002 to assess post-school leavers who were already in, or applying to join, what was then the NSW ATLAS program. Schools (Special Support Teachers) completed the 9 item Functional Screen on each school leaver so that the results achieved with a short functional screen, and the results achieved with the full functional assessments undertaken by the CRS, could be compared.

The first report on "ATLAS consumers and their prospects" was produced in 2002 and in 2003 the first assessments using the new tool were conducted. In 2006 ATLAS became Post School

Programs including Transition to Work (TTW) and Community Participation (CP). Also in 2006 the Post School Programs Classification & Costing Study was conducted, leading to 4 funding bands for CP being introduced. From 2007 onwards the assessment tool has been used to determine eligibility for PSP and, if CP, to allocate the students to the CP funding bands.

The conclusion from the PSP work program is that a classification approach is both feasible and useful when applied to program management in disability and aged care programs. This is the most sophisticated work done in client classification, at least in NSW, because the eight CP classes have been determined by reference to data on costs collected in an extensive costing study conducted with agencies providing services under the program. That means the classes are linked not only to the individual's level of need, but also in a predictable way to the cost of providing the program they are assigned to.

The work in Post School Programs is about assessment, classification and allocation, but does not go on to consider outcomes as such. The standardising and routinising of the measures in these programs means it would be a relatively simple matter to use the same measures at a later time to check whether the young persons' skills or functional abilities had changed and whether this might be attributable to the programs they were using. However, the question of attribution in these types of programs will remain difficult because of the range of additional services and supports that are involved with young people with disabilities.

One-off assessments are practical to assign priority or in this case to determine a classification of the young people, but that this is not the same as measuring outcomes, which require subsequent measures be taken and change scores examined and analyses of other information (both client 'stories' and data on utilisation) to be included.

3.9 2007-2008 – SAFTE evaluation using ONI data

The NSW Sub Acute Fast Track Elderly (SAFTE) Care Program was a pilot program to target older people living in the community who are at risk of presenting to an Emergency Department (ED). The complexity of the clinical, functional and social needs of the client group required a coordinated approach to assessment and care planning and this was facilitated by the routine use of the ONI tools. The standardised assessment tool also assisted in ensuring the consistency of approach to demand management between sites, and allowed for improved comparability of data for the purposes of quality improvement in the targeting and delivery of the services.

However, the '*inter-operability*' of the data was limited by the different electronic systems being used across health and community care. To use the data collected by ComPacks in the evaluation and as part of outcome measurement, the ONI data needed to be manually re-entered into a central repository before being able to be analysed for use in the evaluation. Assuming that inter-operability will improve over time, and that electronic health records require community care domains to be included, then the capacity for using standardised data elements in assessments of clients at different points in time can generate 'change scores'. Change scores across selected key indicators like functional assessment, social and emotional well-being or social isolation scales can then be interpreted as outcome measures to evaluate the impact of interventions or care packages.

3.10 The ONI-N (NSW) in the national Access Point pilot (2008-09)

This work supported the national framework for community care assessment through the implementation of the ACCNA/ACCNA-R/ONI-N and CENA/CENA-R tools in the Community Care Access Centre for the Hunter Local Planning Area, one of the seven trials being conducted in the states and territories. A key decision was to use the existing NSW Government's Human Services Network (HSNet) to enable electronic referrals. By using HSNet, the Access Centre staff can electronically transfer data to service providers with some capacity to download the information

into client management systems used by NSW service providers. The transfer of inbound referral details to the service providers eliminates the need for care recipients to repeat their details and any service history to each provider.

The data from the Access Point trial was used for an internal evaluation for ADHC to determine whether a simplified process of assessment could be designed for clients of high volume service types such as those seeking specific single services such as transport, domestic assistance or delivered meals. In practical terms, that involved understanding the structure of the extracted data and re-ordering that data to support the analysis and produce a series of tables and charts. Half of the care recipients had incomplete profiles which suggested there were errors in the way data were entered into the CIS, or errors in the data export function. These potential sources of error were expected to be easier to investigate and resolve in CIS2

The NSW Access Point is an example of a 'social laboratory' in the field that provides a relatively controlled setting where standardised data for research and development in community care can be gathered and used for multiple purposes. The development of a continuous client record, and improved functionality and inter-operability in client information systems, will make various forms and levels of outcome measurement more feasible.

3.11 ONI-IAM – Intake Assessment Module for ADHC Regions including children with disabilities (2008-2009)

This project developed an Intake Assessment Module with eight domains for use by DADHC's Regional Intake, Referral and Information (IRI) assessors. This module was designed to link to a broader range of domains that comprise a broad and shallow assessment that is only completed when and if the circumstances warrant more detailed information being collected. The outcome of this project also included the software and relevant manuals that were used in the field trial.

To promote a common approach the tool was based on the work in the HACC Access Point Demonstration Project in the Hunter Valley. There were four levels for the tool to be used. Level 1 was information only (callers are redirected), and Level 2 was the intake function. The remaining levels could be used at the discretion of the IRI worker or by a case manager or other appropriate staff to further assess needs.

The design measured the functional ability of the person with a disability and captured any risks to that person in terms of their care situation. These two domains of needs and risks can derive a summary score called a Service Response Classification (SRC). The needs component is similar to the approach used by ADHC in its post-school programs and the algorithm that produces the Service Response Classification for adults is included in the ONI and is similar to that used by NSW Home Care to rank a client's priority for service. The algorithm for children was developed but required further development based on the collection and analysis of a larger data set.

The ONI-IAM project showed the potential to create a 'first generation' version of a set of client classifications that could be used consistently across programs. The use of routinely collected data elements also has the potential to generate a tailored set of outcome measures when the same data are collected at suitable transition points or when undertaking regular re-assessments.

3.12 Summary of findings from previous ADHC research projects

3.12.1 Functional screening as a core domain

Because it is mandated, quick to administer and routinely collected, at the program level, there are three possible uses of the data from the HACC functional screen for:

1. Program planning and monitoring:
 - To measure the functional status of clients using services funded under different programs
 - To measure the functional status of clients in different regions
 - To measure the functional status of clients using different types of community care services
 - To measure the functional status of clients over time.
2. Evaluating and refining the functional measures over time.
3. Research and development purposes, including the potential development of a comprehensive client classification system for the HACC program

Because the screen is routinely collected at the client level in the HACC MDS it works as a core set of items with multiple uses if combined with data from other domains. Although developed for use mainly with the frail aged, the functional hierarchy has proved to be also useful with young people with disabilities in Post School Programs, as well as a key component in priority rating systems in community care and in specific applications such as the Home Care FST where it is also used in aggregate at the program level to make comparisons across service settings.

However a functional screen is just that – a screen – and as such it is intended to act as a pathway into other levels of assessment. It is insufficient in its level of detail to be an assessment that is used at the level of planning care and for specifying service levels. For example in personal care and domestic assistance, an ability to break down a global goal of improving independence into service-specific tasks like bathing, grooming, meal preparation, transport to a day centre and so on, is more useful.

Outcome measures also need to include other scales like the Australian modified Barthel scale, or specific tools to measure characteristics like social and emotional well being or social isolation.

3.12.2 Client goal as the first level in classification

Outcomes have to be linked to the goal of the intervention and the goal of care is useful as the first branch in a client classification structure. No change, or an arrest in the rate of decline, can be a good outcome in some cases. In the ACCNA trial, the goals were relatively simple and illustrate how goals can be built into a classification at the first level. The ACCNA goals of care were to:

- (1) Improve current level of function and independence after a recent acute illness/event
- (2) Improve current level of function and independence (other)
- (3) Maintain current level of function and independence
- (4) Reduce rate of decline in level of function and independence

The model for care planning in the Illawarra Coordinated Care Trial was more complex because it was wider in scope than the HACC program. It showed how 30 classes could cover complex needs and support a broader range of models of care as well as how they can be funded, including levels of case management from complex planning to more straightforward navigation support.

3.12.3 Outcomes assessment, by definition, can't be a one-off event

Outcomes measurement requires a concept of an 'episode'. That implies reassessment rules, based on a protocol, and criteria for when an episode starts and ends, such as pre-agreed time periods (e.g., each 90 days) or some form of natural bookends (e.g. at logical transition points) such as when a young person moves from school to seeking work or community participation.

The work on priority rating for the PADP program on need and predicting capacity to benefit, the ONI intake assessment module shows how initial screening tools might be flexibly adapted to a

range of functions in different programs. The data collected in the ACCNA field trial suggested that further refinement of an index of rehabilitation potential would be feasible. The Post School Programs classification is used to predict the best placement for young people leaving school but because the assessment is a one-off event, the ability to test if the person benefited from the allocation decisions that were made or in fact went to the right program, is not possible.

These examples show how priority rating and classification systems based on a common data element pool are feasible and imply how the different systems can be made more useful by being applied at different points in time. And that implies a continuous record and continuity in the approach across programs. All these issues could be resolved over time as part of a longer-term research and development agenda.

3.12.4 Implications for a longer and systematic work program

The ADHC commissioned projects reviewed in this Section have been re-visited to draw out lessons that are useful for a future program of research and development and to assist forward planning. For a program of outcome measurement to work effectively, there are a number of considerations to take into account in its implementation:

- Before starting on a continuing development process, a first step is to promote a common understanding across programs of key terminology and assessment concepts. These include explaining the purpose of asking about functional abilities when exploring questions of need and risk and the value of asking questions that seek to systematically explore the primary drivers of the need for care and support.
- Implementation of a common approach to outcome measurement can realistically be described as part of the agency's continuing tool development processes, similar to what has occurred with the assessment approach used by Post School Programs. This recognises that demands on assessment and service systems change, as do the expectations of its users, both clients and staff.
- One implication of an ongoing development process is the requirement to carefully estimate the resources needed to back up a staged approach with consistent training and support for assessors at the entry point. Practical experience has already been gained in the Home Care Service where its Functional Screening Tool is used for service priority rating at the client level and to improve efficiency at the program level by enabling comparisons across outlets in different agency settings. Another example is in the community care reform area through the Hunter Access Point trial in NSW.
- A process of continuing and systematic collection, review and analysis should aim to refine a suite of data elements and measurement scales by analysing the data that is collected in routine practice. This is so that the relationships within the resulting data set can be analysed and investigated. Identifying those items that are most commonly used (and/or rarely used) and those that can best predict client and carer outcomes measured at a later time is one aim. Another aim is to reduce the burdens of data collection over time.

There is enough experience already accumulated within ADHC to confidently move towards more systematic outcome measurement. It needs to be systematically brought together rather than having important lessons left inside the various programs, their research projects and reports. The recommended suite of common data elements that includes the potentially useful outcome measures derived from this review of ADHC projects, as well as items useful for organising service responses, is included in Appendix 2.

4 Review of Best Practice in Measuring Outcomes

4.1 Overview

This review of current practice has drawn on published papers from long term research and development programs in the UK, the United States and Australia that are known to be relevant to the topic of measuring outcomes in community care.

Glendinning (2006) from the group at the University of York noted that during the previous decade, discussion of outcomes has become common, as part of a wider service *modernisation* agenda in the UK that has included emphases on increasing the *flexibility* of traditional service provision, performance monitoring beyond counting hours of service provision and more *client-directed* care.

To date, much of the academic literature relating to the measurement of client and carer outcomes has been influenced by work in the health sector. This sector has defined admission and separation points, typically to and from a hospital inpatient setting. The administration of time-limited treatments and therapies contain natural transition points that can be defined as 'episodes'. These episodes are amenable to some sort of measurement that can capture outcomes for patients '*before and after*' an intervention. In this context the measurement of patient outcomes can be very specific and tailored closely to particular conditions and treatments and improvements in the person's condition or functioning after an intervention or hospitalisation are relatively straightforward. Examples are described in Appendix 4.

The same point is made in the extensive social care literature in the UK; outcome measurement related to specific conditions in controlled environments with a 'captive audience' is different to the less controlled environments in community settings where interventions are often continuous, repeated and aimed at maintaining functioning in a context of deteriorating health such as in progressive diseases like dementia (Qureshi, 2003, p.118).

The key message from examining the body of international evidence is that the measurement of outcomes is easier where there are well-defined interventions, clearly articulated goals and ways of defining episodes of care so that standardised measures are repeatable at different points in time.

The review of outcome measurement in this Section has focussed on extended programs of research (rather than specific papers) and was restricted to published literature from 2000 onwards and material available on websites. In order to manage a large body of literature, the review of best practice covers a selected group of the four most relevant research-driven bodies of work:

- Papers relating to outcomes and services for older people and their carers derived from projects carried out under the UK Department of Health-funded Outcomes Programme at the Social Policy Research Unit (SPRU) since 1996.
- The Scottish adaptation of the SPRU health and social care approach that has applied the findings to a broader system of care.
- Lessons from the work of the Picker Institute, a US-based centre with a focus on measuring consumer outcomes in the hospital and broader health sector.
- Contemporary Australian experiences in outcome measurement that are relevant to health services operating beyond acute hospital settings.

4.2 UK Social Policy Research Unit (SPRU) Outcomes Program

The Social Policy Research Unit (SPRU) at the University of York has been the main resource for those seeking to implement client outcome-focused work in the UK. The SPRU developed a government supported ten-year program of research in partnership with a number of local authorities in the UK that was designed to address at least some of the barriers in translating the concept of community care outcomes into practice (Sawyer, 2005).

The list of potential *barriers* to outcome measurement within the community care sector that was identified through this research program is long and equally relevant in NSW as in the UK:

- There are a varied range of clients, programs and services influencing outcome measurement and achievement.
- A range of complex social issues is being addressed.
- The system is in a constant state of change.
- Many outcomes are evidenced only in the long term.
- The lack of obvious end points to interventions and a lack of accepted measures
- The links between intervention and outcome and impact are not always straightforward or definitive.
- There is a culture of non-measurement within the community care sector which reduces motivation and capacity to measure outcomes.
- Organisation issues such as size and specificity of focus. Small community organisations may be reluctant or unable to measure outcomes due to limited resources and measurement may be seen by some to be detracting from service delivery.
- The highly prescriptive, short, task oriented visits increasingly commissioned which militate against care providers' ability to respond flexibly to the changing needs of service users.
- Instruments that have an emphasis on measurement before and after an intervention do not fit the kind of outcomes achieved or aimed for in much of community care work.

Based on their extensive program of research with older people, the team at the University of York (Glendinning, 2008) identified three 'clusters' of desired outcomes for consumers that are described in Table 1.

Table 1 *Three 'clusters' of social care outcomes*

Maintenance outcomes	Are those that prevent or delay deterioration in health, wellbeing or quality of life. These may include meeting basic physical needs; ensuring personal safety and security; living in a clean and tidy environment; keeping alert and active; having access to social contact and company; and having control over everyday life.
Change outcomes	Relate to improvements in physical, mental or emotional functioning. They can include improvements in symptoms such as depression or anxiety that impair relationships and impede social participation; in physical functioning; and in confidence and morale.
Process outcomes	Refer to the experience of seeking, obtaining and using services. Process outcomes are important to the extent that they can enhance or undermine the impact of services that might otherwise appropriately address change and/or maintenance outcomes. Process outcomes include feeling valued and respected; being treated as an individual; having a say and control over how and when services are provided; perceived value for money; and compatibility with cultural preferences and informal sources of support.

These concepts have been used in a number of well-researched development projects addressing the practical problems of applying outcome ideas in practice in the UK. Resource kits have been developed on the basis of this work (Nicholas et al, 2004).

Key to the success of this approach was the recognition that the outcomes must be the service user's own expression, in everyday language with which he or she is comfortable, of his or her aspirations for the service(s).

Outcome measurement used in this way is meaningful for service users and can actively involve them in thinking about and planning for their own care and support. It is also an effective way of moving from the over-rigid prescription of tasks and times in traditional service models to a service which is more able to respond to users' changing needs and preferences (Sawyer, 2005).

4.3 The Scottish experience with the User Defined Service Evaluation Tool

The SPRU outcomes framework was adopted in Scotland as the User Defined Service Evaluation Tool (UDSET), and was implemented in pilot sites and evaluated by the University of Glasgow (Stewart 2008). It reflected the priorities of current health and social care policy across the UK; i.e. that service users and carers should be better involved in decisions around their care and support, and that the support provided should deliver measureable outcomes.

In Scotland, this work was supported by policy in the form of the outcomes-focussed joint performance framework, the National Outcomes Framework for Community Care.

This framework has four high-level outcomes:

- Improved health,
- Improved well-being,
- Improved social inclusion and
- Improved independence and responsibility.

The aim of UDSET was to improve practice through the application of user and carer defined outcomes *tools*, and to enable health and social care partnerships to gather data to determine whether they are delivering good outcomes to service users and their carers. This data can be used to include user and carer experiences in performance management, planning, commissioning and service improvement.

A toolkit was developed alongside the National Outcomes Framework and it can also be used as a standalone toolkit by any organisation interested in the experiences of service users or carers in community care settings. The revised framework (now called *Talking Points*) was then tested in interviews with service users and has been piloted in Scotland since 2006.

The Scottish Community Care Outcomes Framework (Scottish Government 2008) therefore is a multi-level approach that sets its performance framework in the context of frontline working and in support of the key role of assessment, care plans and review:

'Assessment, care planning and review lie at the heart of identifying and improving outcomes for people using community care or support and their carers. The Community Care Outcomes Framework offers a means of understanding how a local system is doing in improving outcomes for people overall. But the biggest impact day to day will come from putting outcomes for people at the heart of assessment, care plans and review.' (p.3)

4.4 The US Picker Institute program – moving beyond satisfaction surveys to measuring personal experiences

Research in quality assurance programs in the health sector usually includes measuring patient *satisfaction* with the quality of the care provided and this approach has extended into community care practice by the use of periodic surveys of the users of services, usually documented in an agency's annual report.

The interest in quality improvement by gaining consumer feedback has resulted in a proliferation of patient/user satisfaction questionnaires (Quintana, 2006). The measurement of satisfaction is a relatively cost-effective way of collecting data, and is often treated as an 'outcome measure'. The assumption is that satisfaction is logically linked with positive changes in health status or improved functioning following treatment or an intervention of some kind.

Satisfaction is considered to be more like a 'process' measure rather than an outcome as such, i.e. it is generally about satisfaction with the way in which care was delivered. However, the results of satisfaction surveys may be biased towards positive results and difficult to interpret (Wiles, 1996). There is rarely a sound basis for service users to compare their satisfaction with what they received with some other service, and it would be logical to assume they would be more satisfied than if they received no service at all. And from the point of view of providers,

"...knowing that, say, 15% of patients rated their care as "fair" or "poor" doesn't give a manager or clinician a clear view of what they need to do to improve the quality of care in their hospital". (Picker Institute, 2010)

The difficulties of interpreting patient satisfaction surveys in the health sector have led to an emphasis on measuring *experiences* rather than satisfaction. In other words, rather than asking people to rate their care on a Likert scale (e.g. excellent, very good, good, fair, poor), they are asked to report in detail on their experience of a particular provider at a specific point in time. This is done by responding to questions about whether or not certain processes or events occurred during the course of a specific episode of care (Picker Institute, 2010).

The measurement of personal experiences is coming to be seen as much more useful than measuring satisfaction (Quintana, 2006). This focus on the details of practical experiences highlights the role that can be played by outcome measures. They should allow a provider to focus on what a person experiences, rather than the provider's own service 'outputs' (hours of service or specific procedures). This more *person-centred* focus should logically help to pinpoint practical problems of quality or lack of continuity more precisely.

The Picker Institute in collaboration with the Harvard Medical School in the USA has developed suitable instruments to measure patients' experience in a program of work where the aim was to explore patients' needs and concerns as they themselves define them. A total of 8,000 patients, family members, physicians and hospital staff participated in one study where patients were asked to objectively report on their experiences and the care provided rather than provide simple satisfaction ratings.

The resulting 'Picker model' outlined 8 dimensions of patient-centred care as the key drivers to service quality:

- respect for patient's values, preferences and expressed needs,
- coordination and integration of care,
- information, communication and education,
- physical comfort,
- emotional support,
- involvement of family and friends,
- transition and continuity, and
- access to care

This model is widely accepted and its eight dimensions were adopted in the Home Health Care Survey in the USA, the WHO responsiveness surveys and the nation-wide NHS patient survey program in England.

4.5 Best practice Australian experiences in outcome measurement

The Australian Research Alliance for Children and Youth (2009) collected the views from community sector organisations as well as those in the public and philanthropic sectors, researchers and others with an interest in outcome measurement. In particular suggestions were sought on applied strategies to improve the evidence base for measuring outcomes of community organisations, the community sector generally and related issues.

The resulting report makes the case for measuring outcomes, reviews the evidence and current practice and summarises current models, frameworks and tools in use across Australia. The report concludes that good evidence on improving effectiveness by measuring outcomes is lacking¹.

While very broad and comprehensive in its scope, the limitations of the ARACY report are its focus on current practice in outcome measurement and performance monitoring in community organisations generically. It did not look systematically at areas where outcome measurement is either well advanced or emphasised in particular service models. The implications of the Victorian experience with its Active Service Model and the measurement of client-level outcomes in rehabilitation and palliative care are illustrated below to give a more rounded picture.

4.5.1 The Victorian Active Service Model

The Active Service Model (ASM) does not contain an outcomes measurement system as such, but is a *plan* for HACC funded services in Victoria with a focus on the premise that clients have the potential to make gains in their wellbeing. A similar model is well developed in WA and a policy direction based on the Victorian model is gaining currency in NSW. The defining characteristic of this most highly developed model is that the starting point for all clients is their strengths rather than their deficits, and that all clients have some capacity to improve. This logically implies a method for assessing whether any improvement has taken place.

This model emphasises the provision of 'person-centred, timely and flexible' interventions that prioritise capacity building and restorative care to maintain a client's abilities to live as independently as possible. The range of strategies and interventions to be utilised as part of an active service model suggest the areas where specific outcomes can be measured:

- strength-based assessment (strengths capable being objectively measured);
- increased access to physiotherapy and occupational therapy (as part of a service plan);
- retraining in activities of daily living (measure functional improvements in specific areas);
- timely provision of aids and equipment (measure functional improvements in specific areas);
- greater utilisation of relationships with community care workers (referrals are made and used);
- encouragement to participate in local health promoting activities (referrals are made and used);
- strengthening social support (measure improvement with specific scales).

There is a growing body of evidence to suggest that such interventions result in substantial functional improvements in frail older adults, and are cost effective in that they reduce (for a period of time) the need for ongoing health and community services for a substantial proportion of clients.

The Victorian ASM shows how community care and support services have been supported centrally to move beyond offering basic care to more complex goals of care for a wider spectrum of their clients. This wider spectrum of clients includes those who may not have had access to this mix of services in the past because of their lower levels of dependency. The implications for outcome measurement are that assessment tools are required that are calibrated to capture

¹ http://www.aracy.org.au/cmsdocuments/Measuring_the_outcomes_of_community_organisations1.pdf

change at higher levels of functioning, and that measure aspects of quality of life and social participation.

4.5.2 Outcome measurement in disability

A recent report on the NSW Disability Services Sector on Directions for Industry Development has summarised the current policy and program level concerns related to improving quality and effectiveness in the sector (National Disability Services 2010).

Like the Victorian ASM, no specific outcome measures are recommended, however the focus on quality improvement provides a similar contemporary context to measuring outcomes for people with disability, placing it within the National Quality Framework. The relevant recommendations (3A, p.44) were that a quality framework should include:

- Clearly articulated outcomes for people with disability, and measurable outcome indicators for each of these outcomes (including measuring the experience of people with disability).
- Objective and consistent processes for monitoring quality across all disability service providers (government and NGO), based on clearly articulated and measurable outcomes and service standards.
- Supporting processes and tools for measuring outcomes.
- Appropriate consequences for good or poor performance.
- Consideration of the need for periodic independent verification of service quality by (independent third party accreditation).
- Recognises equivalent data and evidence requirements of other quality and measurement systems (reciprocity) that would demonstrate achievement of outcomes and compliance with standards, in order to reduce the administrative burden on service providers.

The report does recommend the development of resources and tools to build understanding of quality improvement and measurement of outcomes, so that information about quality and effectiveness can support people with a disability and their families' decision making and choice, and that funding agreements should focus on 'outputs and outcomes rather than inputs' (National Disability Services 2010, p.44).

4.5.3 Outcome measurement in rehabilitation

An example of an outcomes focussed research program relevant to an active service model is in rehabilitation. It has relevance to community care settings. The Centre for Health Service Development has a sub-Centre called the Australasian Rehabilitation Outcomes Centre (AROC <http://chsd.uow.edu.au/aroc/>), which is a joint initiative of the Australian rehabilitation sector (providers, funders, regulators and consumers). It commenced operation on 1 July, 2002 with the goal of improving clinical rehabilitation outcomes by benchmarking rehabilitation providers nationally.

An objective of AROC is the expansion of data collection to non-inpatient care settings, after having established inpatient data collection and benchmarking. The challenge to meeting this objective in an area with such a diverse range of care and service delivery models lies in standardising the information collected, including the relevant outcome measures in community settings.

A draft data set was developed, piloted and refined during 2007/08 with the involvement of stakeholders through the AROC Scientific and Clinical Advisory Committee (SCAC). The ambulatory data set (version 1) is based on the AROC inpatient dataset, modified to include items that relate specifically to evaluating the efficacy of ambulatory rehabilitation programs.

The recommended outcome measure – Australian Modified Lawton's IADL Scale – is the same as that used within the assessment tools for ADHC's Post School Programs. The choice of this

outcome measure resulted from vigorous discussions with major stakeholders regarding the goal orientation of ambulatory rehabilitation as opposed to that of inpatient rehabilitation; namely the focus for inpatients is a return to physical and cognitive functional ability in the self care spectrum, rather than the ability to interact and function in the community independently.

The assumption was that most participants in ambulatory care already demonstrated a degree of functional independence. To this end the Australian Modified Lawton's represents a more sensitive measure of the outcome of ambulatory rehabilitation than the FIM™ as it relates to instrumental tasks, such as a patient's ability to do their own shopping, cleaning, cooking, manage their finances, skills that demonstrate their independence in the wider context.

Within the longer term work program it has been noted that there is a future opportunity, once the ambulatory data collection is established, for AROC to add impairment-specific outcome measures to the ambulatory dataset to provide more specific benchmarking at an impairment level or by type of disability.

4.5.4 Outcome measurement in palliative care

This focus on the details of practical *experiences* in the community sector highlights the role to be played by outcome measures. They should provide a focus on what a person experiences, rather than what services they receive (hours of service or specific procedures). Outcome measures should help to pinpoint problems of quality or lack of continuity more precisely.

A working example of where outcome measures are being used in routine practice in Australia can be found within the palliative care sector. The Palliative Care Outcome Collaboration (PCOC <http://chsd.uow.edu.au/pcoc/>) is a voluntary quality initiative that assists palliative care service providers to improve practice based on measuring what the patient experiences. During the five years of its existence PCOC has demonstrated the value of using and collecting patient level data to review and improve practices in the palliative care sector.

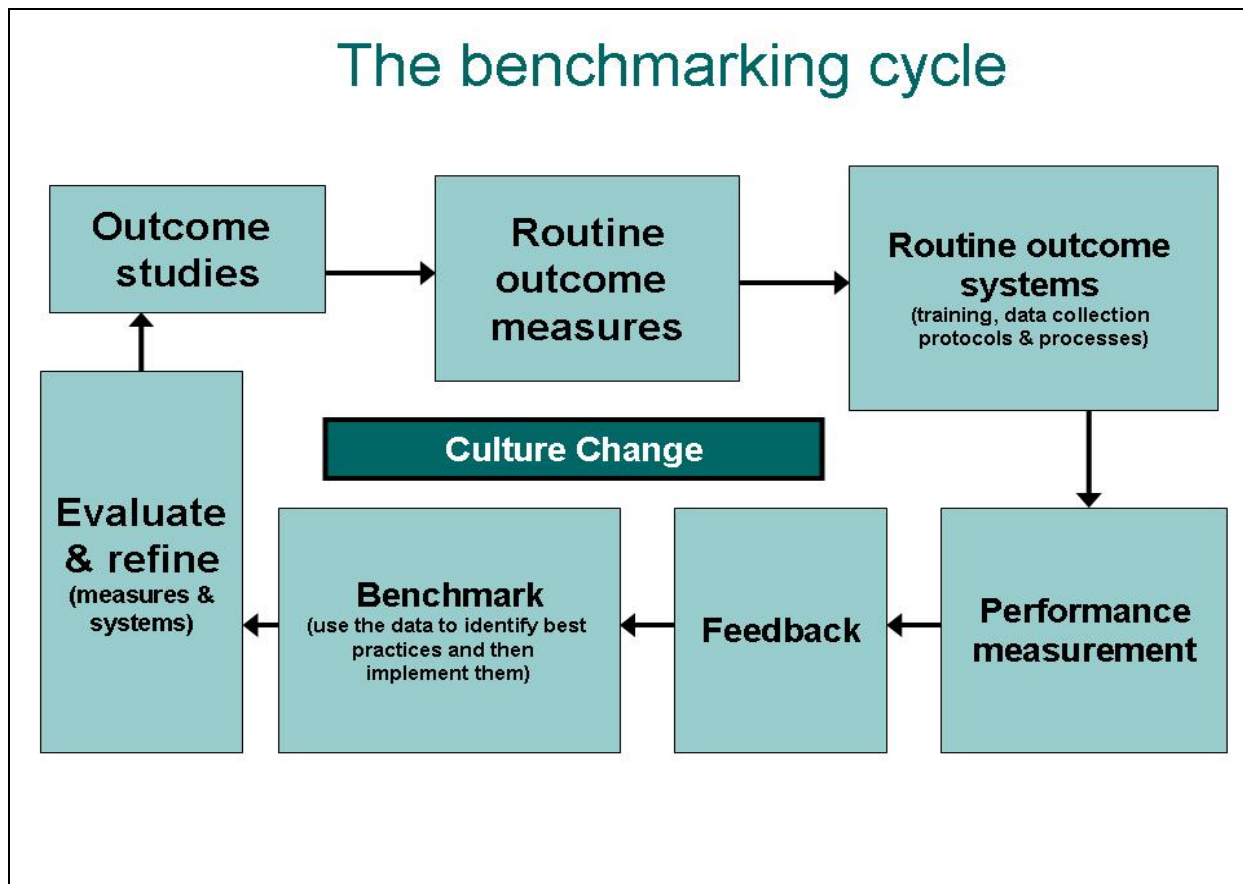
The PCOC dataset is made up of a framework of standardised data items that are used to understand quality at the patient, service, and healthcare system levels. These tools have helped to manage the wide variation in practice that has been found within palliative care service delivery in Australia. In regular six monthly cycles PCOC services receive reports on their outcomes data which can be used to support clinicians in their treatment decisions and assist managers in service planning. In doing this, PCOC has increased awareness of the relationship of data collection to support care planning and also promoted data-driven service development and quality activities. In participating in this process palliative care services have reported improvements in clinical practice and a capacity focus attention on measureable outcomes such as pain scores are clearly relevant to the quality of life of the clients.

This service improvement would not have been possible without:

- a clear understanding of an episode of care, in this case defined as the 'phase' of palliative care, i.e. stable, deteriorating, unstable, terminal or bereaved, to give a common language of care that could be used in communication between providers
- standardised clinical assessment tools, for example the Palliative Care Symptom Severity Score and the Pain Scale.

PCOC services also attend regular benchmarking workshops where they are able to compare outcomes with their peers and discuss quality improvement and best practice measures. The logic model of this benchmarking cycle is highlighted Figure 1 which was described for a presentation to palliative care coordinators in Queensland on the role of PCOC (Eagar 2010).

Figure 1 Benchmarking Cycle



This is the recommended working model for community care outcomes measurement. It also illustrates the timelines to realistically expect. As well as making important progress, as Gordon et al. (2009) point out, the PCOC framework is evolving in the same direction as other client-focused care models and there is still a lot of development work to be done.

“Palliative care continues to evolve at a rapid rate in Australia. Increasingly flexible evidence-based models of care delivery are emerging. This article argues that it will be critical for equally flexible funding and financing models to be developed. Furthermore, it is critical that palliative care patients can be identified, classified, and costed. Casemix classifications ... represent an important starting point but further work is required.”
 (Gordon et al. 2009, Abstract)

4.6 Summary of issues for developing routine outcome measurement in NSW community care

The outcome measurement issues for providers, particularly where clients’ problems and needs are understood in social terms as well as medical conditions, are linked to the difficulties of attributing changes to any particular intervention or mix of services. Understanding the impact of case management has similar difficulties because the intended outcomes of case managed community care programs are generally under-specified (Simpson-Young and Fine, 2010).

What we can measure in the NSW community care sector are the outputs of services plus time used in assessment and developing care plans. These outputs are measured within service reporting systems and care management systems as levels of service provision at the agency

level (e.g. the numbers of clients) and throughput such as the numbers of discharges, occupancy rates and turnover (Simpson-Young and Fine, 2010). None of these measures address what has been achieved for clients and carers from the activities, and while providing accountability for budget allocations, this is different to measuring the *effectiveness* of the money spent (Sawyer, 2005).

In an attempt to simplify the approach to measuring outcomes it is helpful to think in terms of a hierarchy of outcomes (Sawyer, 2005). For example, whilst the over-arching outcome might be for an individual to regain independence and control over their own life, progress may be better monitored if there are a series of 'bite-sized' outcomes, such as being able to:

- make a simple meal
- dress and undress without help
- wash or shower on his own
- organise own shopping needs.

This approach could be applied to the whole range of other activities of daily living as necessary, as determined by the needs of the service user. In Sawyer's (2005) words, based on the UK experience:

Not only is this likely to give the individual a more rapid sense of achievement but also it will enable staff to focus more clearly on specific areas. If complete independence is not achievable it will provide clarity about the areas with which there may need to be continued help and it may also enable a more sensitive and appropriate reduction in service provision. (p.4)

Building systems for routine goal setting and practical outcome measurement using standardised tools is not uncharted territory outside of institutional settings and beyond acute care in Australia.

Despite the challenges of greater diversity in clients and service types there are signs of a shift of measurement focus in the community care sector, from efficiency alone to efficiency and effectiveness. Measuring outcomes is now being pursued by a number of organisations and is being widely encouraged by the government and private sector. Agency-level perspectives in NSW were investigated by interviews and the review of documents, and these are presented in Section 5 below.

5 Agency Level Perspectives on Outcomes

The aim of this element of the exploratory study was to ‘triangulate’ our conclusions from reviewing the published and practice literature with NSW and national experiences, and lessons from discussions with innovative providers and with a small number of their clients. This was not a comprehensive survey and its primary purpose was to assist the synthesis of the relevant findings to inform our recommended model based on palliative care and the set of data items we have reviewed and selected as being most relevant for measuring outcomes in community care settings (list in the table in Appendix 2).

5.1 Feedback from consultations

Current data collection protocols

There was agreement that current data collection protocols are burdensome. They are also too focussed on outputs (e.g. number of service hours) and eligibility rather than outcomes.

These factors are complicated by the number of programs a particular agency can be involved in at any one time. One service provider commented:

The myriad of program reporting requirements has created a compliance challenge. We are currently involved in 34 different programs under ADHC which require the collection of various quality assurance and output measures such as contact hours per service type.

It was agreed that most of the data elements currently collected are linked to funding at the organisational level. Many care workers believed that this data collection proved to be a distraction. In the words of one care worker:

The requirements of various reporting systems affect our responsiveness to clients and carers

It was stated that the only outcomes data that services routinely collect relate to annual satisfaction surveys at the organisational level. These data are usually aggregated and sit in annual reports and add little meaning to the client/care worker interaction. There was widespread agreement that the change management issues and cultural change issues involved when focussing more on outcomes measurement will take a long time.

What makes for a good data collection tool?

There was agreement that a good outcomes data tool needs to be client focussed and needs to be flexible enough to combine useful data with the client’s ‘story’. One care worker commented:

It is important not to rush the data collection and to assume that it will be ongoing. Data collection tools should also help us hear the ‘story’ behind the ‘outputs’. The tool should open up a dialogue with the client.

There was also agreement that data management systems such as The Care Manager should not just be a repository for data elements. A good data management system should have the ability to ‘talk two ways’, i.e. be able to collect data and report on data in a meaningful way. The system should also be flexible enough to allow for additional fields to be created which are relevant for evaluation of other service activities as required.

A move towards wellness and re-ablement

There was widespread awareness of the current initiative in community care towards a wellness and re-ablement approach. One organisation was currently participating in an ADHC funded pilot to test new ways of working with older people who are eligible for HACC but need only low levels

of care. The tools developed to measure the outcomes of this project are very goal orientated to measure relevant domains of well-being across. In the words of one care manager:

The tools are more functional and practical and as a result are more conducive towards care planning and outcomes.

The agency level consultations with two other service providers showed similar data collection tools, selected after pilot testing. One of these services had developed/adapted tools to measure wellbeing in the domains of overall quality of life, mental and emotional (control/autonomy and mental health) and social (social isolation/loneliness). The tools adopted included:

- Autonomy and Control: Impact on Participation and Autonomy (IPA)
- Social connectedness/sense of belonging: UCLA Loneliness Scale
- Emotional/psychological wellbeing: Kessler Psychological Distress Scale (K6)
- Overall wellbeing: Personal Wellbeing Index (PWI)
- Wellbeing of clients with dementia: Quality of Life AD (QoL – AD)
- Carers: Caregiver Reaction Assessment (CRA)

These tools are being piloted in two HACC Community Options programs and one CACP program. Care workers involved in the pilot expressed some concern over the carer tools as they were perceived to be 'too negative' with the focus on carer strain and distress. Care workers also had some concern over the negative framing of other tools (e.g. K6 and the UCLA Loneliness Scale).

Overall, the feedback of using the tools was very positive. In the words of one care manager:

Once the staff started to receive quarterly reports about their clients as a result of using the tools they were 'hungry' to use them more and more.

Issues in setting client goals

There was agreement that goal setting for clients is a useful element of community care assessment. One agency observed that the generalised goals of maintaining independence in the home and reducing the likelihood of entering residential care were commonly reported as the aim of service provision, but were not helpful in practice as they were simply a restatement of the HACC Program goals at too high a level of generality.

However, goals were said to be important to emphasise and it was also felt that this would need to be done in combination with providing both common and practical measures that could be used to set achievable goals. These were to increase muscle strength or body flexibility, or at the more dependent end, being able to get to out of the house or get to places out of walking distance. These might be goals set with reference to functional screening tools or where relevant to the client's circumstances, other psychometrically well-tested tools such as measures of carer burden or social isolation.

There was concern that without good back-up to goal setting, like training or more automated systems, care workers would prefer to just talk to their clients rather than go through a complicated and time-consuming goal setting or goal attainment scaling exercise. A compromise was judged to be where a conversation could be translated into a set of goals by the service provider and then put in a plan of care and support that could be checked back with the client or carer.

There was also concern about the discouraging effects of recording negative scores for goal attainment if clients' goals have not been met. Negative scores at the service level were also felt to be an issue, as highlighted in the following comment:

What happens if the GAS scores go down at the service level? Could this be seen as a reflection on service quality? If this is the case there would be nothing to stop a service 'gaming' their results.

In view of this it was felt that there should be clear guidance from a training or education package about the best strategies to adopt where goal attainment reveals a negative outcome.

Recommendations from agencies for ADHC

It was widely agreed that the myriad of reporting requirements should be simplified and where possible be consistent across programs. Most informants were aware of and agreed with the directions proposed in the recent 'Red Tape' report about reducing the complexity and redundancy in various systems. It was also agreed that data collection should move beyond collecting data on service hours. The following three quotes sum up this position:

Multiple assessments complicate outcomes...we need to reduce the amount of 'red tape'...we need a basic reporting system in place which fits across all programs.

Data collection should not be focussed only upon collecting just 'another bunch' of numbers representing service types or hours.

We need to standardise data collection in a meaningful way – any measures developed have to link in with things that you do in practice – needs to inform care planning and case management – tools developed need to be functional and practical with less emphasis on counting 'widgets'.

Another theme was the importance of feeding back the analysed data to the care workers that collect it, i.e. to create the 'virtuous loop' where continuous improvements become possible because relevant data are collected, then turned into useful information that can be used for improving the way that services are provided.

This would benefit ADHC program management in relation to planning their quality improvement initiatives. Feedback to regional planning processes could link client demographics and service information with outcome data to look for relationships such as the levels of client dependency in different service types, or across different agencies in a region with similar target groups.

It was also stated that any decisions on how to proceed to a more outcomes focussed approach to data collection should be made on a sector-wide basis, so that individual service providers do not 're-invent the wheel' in their efforts in measuring client outcomes.

In the context of national and state reforms, the chance to build an outcomes measurement approach into data collection in the community care sector was judged by the agencies consulted to be difficult in practice, but with potential to create net benefits, not only to the service providers, but also to ADHC program management. It would encourage better reporting compliance and useful feedback to service providers to voluntarily improve their routine practice.

5.2 Implications of the findings

The pattern of the interview responses from care recipients indicated the importance of outcome measurement approaches capable of registering change *across the care continuum* from wellness promotion through maintenance to end of life care. The current range of useful outcome indicators built into some programs are mostly about functional dependency and very likely to have ceiling effects for the clients in the early intervention end of the intervention spectrum. Those clients who have more traditional care and support goals can benefit from simple quality of life and social participation indicators and those clients receiving support at the end of life require simple to administer and standardised indicators of quality of life such as pain scales, symptom severity scores and indicators of carer burden.

6 Discussion of the findings in the reform context

6.1 Structural reforms

Recent national-level decisions effectively establish a four to five-year time span to plan the details of a more effective system of community care. In aged care this will be a Commonwealth-funded system and in disability it will be State-funded. Both systems can benefit from a consistent approach to measuring outcomes and there will still need to be ways of managing clients' transitions between the two systems.

Decisions of the Council of Australian Governments (COAG) and the health reforms, the impacts of recommendations from Productivity Commission reports and disability reforms in long term care and support all point in the direction of measuring effectiveness from the user's point of view and developing more shared rather than separate systems.

Consistent with the COAG NHHN Agreement in relation to Primary Health Care Organisations (PHCO) or 'Medicare Locals' as they were renamed after the 2010 Budget, the proposed new regional structures could have roles and partnerships that extend beyond that proposed in the COAG agreement. It could directly manage all community and population health services, be they funded by the Commonwealth or the State and it could also have key responsibilities for the coordination and delivery of Commonwealth funded HACC and community aged care.

6.2 Implications of national reforms for outcome measurement

The interlocking reforms are complex and their implementation will necessarily involve working out compromises, and the need to accommodate regional issues. However, a useful set of guiding principles may be able to be articulated, using common tools and methods of analysis is possible and a shared vision within and across departments, agencies and community groups may emerge over time. Some of these components are summarised in this section.

6.2.1 Classifying clients based on need

Hospital reform, in particular the shift to activity-based funding, implies increasing sophistication in the classification of patients and the costing of service provision, both inside and outside of acute care. Classification-based allocation models like in ADHC's Post School Programs, and demand management strategies as seen in the NSW Home Care Service's use of their Functional Screening Tool, are current examples of evidence-based strategies to encourage movement in that same direction.

6.2.2 Local-level planning roles

Population level planning and fund-holding roles under Medicare Locals are being proposed in areas of 'market failure', and this recognises the limitations of a dominant fee-for-service model that has evolved under the ad hoc reforms in providing greater access to allied health services under Medicare. This planning function – which has to be for the whole community, not just those enrolled in GP practice networks – is proposed to include the development of a *Healthy Communities Report* for each Medicare Local's catchment area....'A Healthy Communities Report will be developed for each Medicare Local's local area, as part of the performance and accountability arrangements built into the new National Health and Hospitals Network.' (Health Portfolio Primary Care Statement p.27)

Medicare Locals are set to be independent legal entities (i.e. not government bodies) with strong links to local communities and 'some common governance membership with the Local Hospital Networks in their region.' What that structure will look like will depend very much on local

conditions, but common methods and models will evolve over the next five years. How to build the right sort of hybrid public-private and community-based 'space' for the planning and delivery of primary and community care is probably the biggest 'unknown' at this point, but the time scale proposed suggests there will be time to work this out, and the shape of a viable community care sector space is becoming clearer after the recent Federal Budget.

The potential advantages for community care within, or even on the edge of health sector reforms, are going to be in strengthening a set of non-institutional services in the community sector, building the capacity to address local health concerns apart from more fee for service medicine, and forming useful alliances across sectors, and 'responsible for a range of functions aimed at making it easier for patients to navigate the local health care system and to provide more integrated care.' (Health Portfolio Primary Care Statement p.27)

6.2.3 A common focus on demonstrating effectiveness

The proposed Healthy Communities Reports would be a means of supporting the use of regionally managed data reporting on the effectiveness of community care as recommended by the Productivity Commission. Profiles of local service users in different programs, based on functional dependency scores, can provide a snapshot of client characteristics and changes in scores for individuals over time would be able to provide outcome indicators if they were interpreted by being linked to the goals of care. Change scores that show improvements in function would be useful where the interventions have 're-ablement' aims, while maintenance and support services would benefit from systematically reviewing their clients changes in dependency linked to the intensity of their service provision.

The health and aged care reforms may eventually be able to come together with the disability reforms by all three sectors contributing to common ways to understand need and measure outcomes. These may emerge in the planning to manage the transitions from state to national funding and from consideration of client pathways, for example from hospital to community and from disability to aged care. A common model will also be useful for understanding the needs of people with a disability as they age and the costs of long-term care and support for people with mild to moderate as well as severe and profound disability.

6.2.4 Improving continuity as a reform goal

The NHHN agreement says the new arrangements for basic community care maintenance and support services 'will be carefully managed to ensure continuity of care for clients' and 'the Commonwealth and States share responsibility for providing continuity of care across health services, aged care and disability services to ensure smooth client transitions.'² That implies the importance of common systems for understanding need and managing care.

Some common aims are to replace (and/or supplement) the existing funding systems for eligible populations with systems to ensure a range of support options are available, including more capacity for individualised approaches. Coordinated packages of care services is a common aim, which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available either short term or for a person's lifetime.

Appendix 3 in this report includes a model for care packaging based on the goal of care and a classification approach, developed for a national coordinated care trial. It shows how a system of costed care packages might work in practice and would be relevant to improving continuity and individualised funding models in both community care and disability services.

² ACSA NSW and ACT Community Care Advisory Committee Policy Update Monday, 3 May 2010

7 Conclusions from the exploratory study of outcome measurement in community care

This report started with a review of one research group's research and the summary of that work explained why a classification approach is useful in the community care sector. However, the findings from over ten years of ADHC-funded research on assessment systems and approaches to priority rating and classification of clients do not automatically add up to a systematic program or common approach to outcome measurement.

Nor is it possible to simply borrow systems for community care outcome measurement from the health sector where they are more highly developed, because community care has important differences (Qureshi 2003), and does not have equivalent concepts of an episode of care, nor agreed and useful classifications.

A systematic outcome measurement program starts from high-level agreement on the usefulness of a common core pool of data elements such as we have listed in Appendix 2. When community care agencies are routinely collecting data about their clients and carers, then a large of data set can be accumulated, and it is then possible to ask and answer more specific questions that can improve the whole system over time. This empirical approach was referred to as 'data-driven solutions' in the research on priority rating for NSW Home Care (Stevermuer et al. 2003). That approach is built into the items selected for the ONI-N and is also a strong feature of the development pathway in Post School Programs (Eagar et al. 2006).

The Home Care and Post School Programs research commissioned by ADHC do contain key elements of what characterises the sustainability of programs; the standardisation of processes and the building of those processes in routine practice (Pluye et al. 2004).

A structured program of research that includes standardising and routinising the collection of information also characterises the community care outcomes research and continuity of care work program that was developed in the UK in the University of York (Nicholas et al. 2004, Sawyer 2005, Glendinning, 2008, Parker et al. 2010). It is also a feature of the user-defined outcomes approach to community care in Scotland (Cook et al. 2007).

The consultations with community care and disability agencies and their clients highlighted how a greater amount of standardising of the data collected is possible outside of institutional settings in NSW. They also said it is advantageous to make a development pathway in outcomes research that is transparent and participatory because the predictors of outcomes, along with predictors of utilisation will be useful to agencies in the field if they can be standardised and routinised as 'evaluation-friendly tools' at the agency-level.

The recommendations in Appendix 5 outline the steps that can be taken in moving systematically to develop an outcomes focus. It is important to clarify these logical steps in a development pathway at the start while assuming that the pathway will evolve as learning takes place based on research and development. That pathway assumes a classification of clients is a key component, using their goal of care, level of function, social environment and carer status as the variables that can be used as the starting point.

The recommendations also assume that developments in NSW should be part of a nationally agreed classification structure in community care and that this approach is a more reliable way to collect and use and re-use valid data on clients in a transparent process that can lead to systematic outcome measurement. A research and development pathway towards a sound classification will give ADHC various ways of comparing like with like, initially based on the goal of care, levels of function, social participation, and carer status.

Appendix 1: The evidence from previous studies and associated research

1. 1999 Developing a Classification of Community Care and Support Services' Consumers in NSW (ADD and NSW Health)

This project explained the principles of classification and how they are relevant to the community care sector. It included a review of current practice at the time and proposed a development pathway where the aim was to clarify and modify the use of a data item pool over time, based on routine client data collected at initial assessment and at transition points where re-assessment is conducted.

The report deliberately proposed focus on a broad array of client groups, rather than a narrow program-dominated approach and anticipated the current national reform context by covering community health, aged and disability clients. The report's definition of who should be included within the scope of the classification was:

“A consumer is a person for whom a human services agency accepts responsibility for assessment and/or intervention as evidenced by the existence of a unique client record. Families/carers are included in this definition if interventions related to them are recorded in the consumer record. If a separate record is created for a carer, they are a consumer in their own right.”

A community care classification was defined as a classification system that grouped clients into mutually exclusive classes based on their need for services. That is, every client should fit into one and only one class although, over time, a client could move from one class to another. Clients who have similar needs should be in the one group and clients who have different needs should be in different groups.

The rationale given at the time for this approach was essentially one of promoting greater equity in resource allocation over time, based on the assumption that if funding is equitably distributed, and providers are equally efficient, then clients who have similar needs could be expected to be receiving similar levels and types of services. This more equitable approach can only be tested and refined once a community care classification is available.

Tools for measurement in the community care sector need to reflect the complexity of the clients within the system. There is little sense in attempting to simplify the processes and outcomes of the community care sector so much that the measuring tools are not relevant to the 'real world' or if the model used isolates community care from the work of other sectors.

Implications for outcome measurement

The report emphasised that a common approach to classification is desirable and clearly feasible and suggested that the problems are not so much technical as organisational, cultural and political. A clear and incremental development pathway and an associated communication strategy were expected to overcome most problems if the human services agencies in NSW were committed to work together to develop a common community care classification. The proposed next step was to develop the detailed and practical work program to turn the ideas into a reality.

2. 1999-2000 National Dependency Data Items (HACC Functional Screen)

This national project's aim was to design tools to be routinely used to capture the functional status of the HACC population as a first step in measuring consumer needs and relating those needs to resource use. The need for these tools had been highlighted for nearly a decade through

numerous reports. However, while functional capacity is of critical importance in driving the need for HACC services, it is not the only measure of need or the only client-related cost driver.

The report and the associated publications emphasised that other important client-related drivers (as assessment data items or variables) also need to be captured to gain a comprehensive picture of the HACC population. The variables of particular importance (among others) for assessing urgency and determining priority for service are age, medical conditions and diagnoses, carer availability, risk of abuse and care setting.

The 9 items in the screen represent a 'functional hierarchy' which are designed to cover the domains of self care, domestic functioning, cognition and behaviour and to prompt more detailed functional assessments that are required to plan the details of providing care. Subsequent developments have demonstrated how the screen forms part of a modular system and how it can be used to determine a priority rating and predict capacity to benefit.

The conclusion from the report was that a common approach to the measurement of client dependency is desirable and clearly feasible and that the technical issues are complex, rather than difficult. A clear and incremental development pathway and an associated communication and training strategy should be able to move the broader recommended approach forward, with each stage being seen as a new 'generation' of an increasingly refined MDS for the HACC program.

The recommendations were that functional measurement be undertaken on a routine basis across the whole spectrum of HACC services in Australia and that functional data be included in the HACC Minimum Data Set. These specific recommendations in relation to the functional screen were subsequently implemented.

At the national level, there are three possible uses of the data: for program planning and monitoring; for evaluating and refining the functional measures over time; and for research and development purposes, including the potential development of a comprehensive client classification system for the HACC program

Implications for outcome measurement

The findings from this work constituted the important first steps in moving towards the development of a comprehensive client classification system for the HACC program. Using that classification to measure need and inform resource allocation decisions would be the next steps and when used at a point of re-assessment, the functional screen could also function as a simple and practical outcome measure.

A suitable work program to keep a measure of coherence in a development pathway was one of the key issues to resolve if the range of relevant human services agencies and programs were to be helped to work together to develop a common approach. Subsequent work has demonstrated that development of a common set of tools and an agreed model is technically feasible.

However, a common and coherent national approach to implementing these tools, including for routine outcome measurement, has not been straightforward, in part because they need to be embedded in larger assessment and client information systems. The proposed incremental development pathway has not been established, but rather a set of additional pieces of work have been commissioned with some cost to the required continuity in the details of the approach.

3. Coordinated Care Trial Evaluation (CCT)

This evaluation was part of the Council of Australian Governments (COAG) reform agenda of the 1990s and was one of two trials in NSW covering health and community aged care in the Illawarra and in Hornsby-Ku-ring-gai. The trial was essentially about a case management approach, the

evaluations were well resourced and the agencies involved drew useful and lasting lessons from the significant investments that were made at the time.

The trial demonstrated that the assessment tools used were predictive of outcomes. When all the variables were fitted together, only two were significant (cognitive and instrumental functioning). Just two assessment tools (physical motor and social function) produced a model that accounted for almost as much of the cost as the model including all assessment variables.

The evaluation reports provide an extensive literature on models of care, evaluation methods and measuring the results of interventions that have subsequently been used for local planning purposes.

A useful document is the refined CCT model of care that was developed in the planning of the proposed second round of the trials, based on the lessons learned. The model was designed for defining consumer needs in terms of a classification approach, and that classification was linked to community care interventions and care packages. A typical package of care for consumers in each class was developed. Proposed packages for the 30 classes were included in the model (see Appendix 3: Illustrations of models from a range of CHSD projects – Recommended consumer classes for the Illawarra Coordinated Care Trial Care Packages). Each Care Package has potentially three elements: one-off expenditures such as home modifications; medical services; and planned community care.

In the model it was not proposed that all consumers in a class receive only a standard care package. Rather, the purpose of developing the standard care package was to determine an agreed *maximum* funding level for each class. Each consumer would be assessed and, arising from that assessment, allocated to one of the primary classes. After assessment, the consumer would be allocated to a trial case management / fund-holding agency and, within that agency, to a designated case manager.

Implications for outcome measurement

Outcomes in coordinated care depend on the goal of care or the care package being offered. The goals of care in this model were linked to the aims of the trial and were primarily health-related sub-acute care goals for the avoidance of hospital episodes and the management of transitions to residential aged care. The groups of client classes, based on the CCT goals of care were:

- palliative
- rehabilitation/functional gain
- evaluation and management
- maintenance and support
- prevention and early intervention
- acute and post-acute

Under each goal, the classes were determined by a series of 'splitting' variables where a characteristic or a score on a standardised scale determined the branch of the classification 'tree' that an individual client would be assigned to, based on their condition, level of functional need, carer status and age. The classes were designed to include 4 levels of case management and a diagram illustrating the model is included at Appendix 3. Each class was linked to a costed care package that could be tailored to the specific needs of individual clients.

4. NSW Home Care Priority Rating

The NSW Home Care Service (HCS) implemented the nationally mandated HACC dependency data items in the HCS Referral and Assessment Centres (RACs). By commissioning the CHSD to use a data-driven approach, the HCS developed a priority rating system based on the Functional Screening Tool (FST) that is appropriate to HCS clients.

The project used existing HCS data plus the HACC functional screen items to develop a working model for the first data collection. The second data collection then tested the working model developed using the first data set, further supplementing it with two data items from the Ongoing Needs Identification (ONI) carer profile (carer availability and status). The analysis of the ongoing data collection was then used to strengthen the working model.

The database to support the data collection was modified for routine use and that enabled the automatic calculation of priority category and prompts for functional assessments required for each screen to be available in real time. The agency has recently confirmed that this option provides a transparent and objective tool with which to manage capacity in a high demand agency.

The HCS model was based on three factors. The first is the functional status of the client (as measured by the 9 items in the HACC functional screen). The second is whether or not the client is at risk due to either cognitive or behavioural impairment (the 2 relevant items in the HACC functional screen are used as a proxy for a full psychosocial profile as captured in the ONI). The third factor is carer status (as captured by 2 items from the ONI carer profile – carer status and carer availability). The model can be illustrated as a decision tree and is included in Appendix 3.

The research establishing this system was planned as the first stage so that it could be implemented to help manage demand and a mechanism of audit and quality assurance was recommended to keep it running as well as contribute to strategic thinking and policy debates.

The FST is set up within the ADHC Client Information System (CIS) and used routinely for each referral to HCS. This is now firmly embedded into the Referral and Assessment Centre (RAC) processes since the CIS was implemented for RAC in November 2006. Branch capacity and FST Category range is updated in CIS by the branch managers and referrals are progressed for assessment based on the parameters set by the branch, CIS then compares the outcome of the FST assessment i.e. category, and current hours capacity at the specific time of referral. These details are recorded in CIS for each referral for future reference if needed.

Implications for outcome measurement

This project was framed within a broader research agenda across several programs and state jurisdictions and it shows that routinely collected HACC data can be used in real time to create a workable decision-making tool that is able to be implemented and used to improve efficiency. It does this by giving each caller a service priority rating, and also demonstrates how the HACC functional dependency items can be implemented in routine practice to improve efficiency. Training was important, as was a planned introduction of the new tools without creating excessive and additional burdens on staff. This is more likely to be the case if the new tools are used to replace less useful tools.

The future for this work also depended upon how broadly it was able to be used to develop intake systems with common features and methods across programs. Ideally the features are embedded in wider systems such as HSNet and in collaboration with other ADHC programs and NSW Health. The logical next step was seen as building the model into both a system of electronic referral of the larger suite of ONI items and into ADHC and Home Care's main database for client information. The priority rating categories are routinely used by Home Care as a form of classification that enables comparisons to be made across branches on the basis of the dependency levels and risks of the clients being assessed for services.

5. State-based Assessment System Design Projects (2002-2006)

A series of linked projects in NSW, Victoria, South Australia and Queensland were carried out on assessment system design in community care, particularly aimed at standardising intake

assessment using the Ongoing Needs Identification (ONI) tools and in Victoria the Service Coordination Tool Templates (SCTT).

During the period 2002-2006 the projects were linked in the sense that each separate piece built on what had been previously carried out. For example the project in Victoria to build the assessment system for electronic referral, used routinely by the Primary Care Partnerships (<http://www.health.vic.gov.au/pcps/coordination/tooltemp.htm>), was commissioned following the national work on the HACC functional screen with the aim being to develop additional assessment modules to cover the domains relevant to primary care. The work in SA implemented a modified (but essentially similar) system to Victoria in a series of pilot areas and with a metropolitan domiciliary care service and an independent evaluation was carried out.

In each iteration important design features of a larger system were able to be carried forward and further refined and field tested. For example the work on priority rating for NSW Home Care, because it was data-driven, was able to be used as the foundation for the priority rating system built into the Queensland ONI as it was being implemented State-wide. Considerable investments in training and regional support systems were made in both Victoria and Queensland to back-up the introduction of the new assessment tools, including a CD ROM version of a self-directed learning package.

In NSW, the projects and trials in this period used the Queensland ONI as the currently most refined version of the intake assessment tool based on the core functional dependency items and associated modules. One additional benefit of using the Qld ONI is the level of support available online (<http://www.health.qld.gov.au/hacc/ONInteractive.asp>).

An evaluation of a set of Comprehensive Assessment System pilots using the ONI was carried out and part of the learning from that period was about the amount of work required in local settings to carry out pilots in complex systems, negotiate protocols for roles in assessment and the importance of a clear policy direction and consistent support from within the (then) Department (http://chsd.uow.edu.au/Publications/2004_pubs/nsw_comprehensive_assessment_pilots_evaluation.pdf).

In parallel at this time, the NSW Community Options Program was routinely using the ONI in its contracts with NSW Health to support hospital discharges and other related packaged care and care planning demonstrations, such as the Sub-Acute Fast Track Elderly (SAFTE) pilot. These different uses of the same system were mostly paper-based, but the functionality of the data elements was facilitated by building the ONI modules and items into case management systems such as The Care Manager.

Another important variation at this time was the use of the ONI in the nationally-funded (under COAG agreements) NSW Mid-North Coast Coordinated Care Trial which was carried out in Aboriginal communities. New items relevant to needs assessment in these communities were added at this time and the system was used to collect data for the independent evaluation of the trial where limited conclusions about outcomes for clients were able to be made.

Implications for outcome measurement

The primary attribute of the Qld ONI was that it is standardised, covers wellness and carer domains as well as the common HACC program areas, and is in routine use. The ONI systems were designed to be used at intake but the 'Ongoing' in the title reflects their use as an updatable and continuous record that potentially can be used to derive change scores on re-assessment and that can support outcome measurement more broadly than one program.

The Victorian Service Coordination Tool Templates have had a consistent development and re-development pathway (<http://www.health.vic.gov.au/pcps/sctt2012revisionproject.htm>) so they are able to be updated over time, with new versions every three years, so there is potential for incorporating a stronger outcomes focus within that pathway. This process to date has reflected

the broadening needs of the health and human services sector practicing service coordination and the redevelopment has responded to requests for common practice standards and tools to support the collection of consumer health and care information and to reduce the burden of collecting information more than once.

The current cycle of revision of the SCTT, known as the SCTT 2012 revision process, has commenced. It confirms the value of having a common and broad approach with new templates and items for carer's information, palliative care, social networks, chronic disease and complex conditions, people with intellectual disabilities, Aboriginal and Torres Strait Islander consumers, and new validated screening questions for problem gambling and alcohol consumption.

The Victorian and SA Initial Needs Identification systems, the Queensland ONI, and NSW Community Options and Mid-North Coast Coordinated Care Trial all used paper-based systems that were designed with electronic data transfer as an option. In Queensland the implementation was assisted by the use of Interactive Free Text PDF ONI Profiles is an electronic option in routine use and backed up by the ONI CD Rom Self Directed Learning Package for training.

Training has been provided more recently in Victoria on a similar model to Queensland through a train-the-trainer model. Victoria has also developed what it calls 'implementation products' for vendors of client management software applications including functional specifications, a data dictionary and data model, HL7 messaging standards, and decision support.

These examples show the levels of ongoing investment required to build a better system of community care information. As the Victorian SCTT program has shown: 'Service coordination aims to place consumers at the centre of service delivery - ensuring that they have the access to the services they need, opportunities for early intervention and health promotion, and improved health outcomes.' Those investments in continuous development and revision, training and electronic support provide the platform needed to systematically measure outcomes.

6. National ACCNA and CENA trials for the Way Forward (2005-2008)

These projects developed Version 1 of the Australian Community Care Needs Assessment (ACCNA) and the Carer Eligibility and Needs Assessment (CENA) instruments. A four level national field trial of both tools was conducted in 2006 where the acceptability and useability of the data elements were confirmed, leading to a series of recommended next steps to resolve technical issues involved in their further development.

The judgements from the field trials were that the ACCNA and CENA were sophisticated tools that, because of their modular structure, could still be used in a straightforward way with those clients or carers whose needs were less complex, and that the information they gathered was of higher quality than much of what was being routinely collected. The tools were also seen to be more 'interactive' with assessor judgements than what is (mostly) routinely being used in the field.

Feedback from the field testing was that the ACCNA and CENA should be designed so that they can 'inter-relate' and be linked in a way to allow information to be 'pulled through' so that information about the carer and care recipient is consistent in both instruments.

The tools were designed for electronic systems, but due to the complexity of the various agencies' information systems, the trial included more assessments than expected that were completed on paper. This reduced the utility of the tool because of losing the advantage of using the electronic prompts and auto-populating functions that were built into the design.

The additional fields added to the functional screen asked about 'who helps' and the degree to which needs are currently being met. This useful addition is a way to measure unmet need.

The trial again demonstrated that the functional profile was able to be used in routine practice to understand its relationship to a number of related client attributes. Relationships between rehabilitation potential, function and other factors were able to be explored to a limited extent within the data collected. A set of clear relationships were found in the data where clients were identified by the assessor as likely to benefit from rehabilitation or what is currently being called a re-ablement or wellness approach, so that a referral for a rehabilitation assessment could be confidently recommended.

The data in the final ACCNA report showed how the relationships at the item level for the functional scores could be used for developing indicators of a client who might benefit from a program of rehabilitation. They would be:

- More likely to need help with housework. Those at the extremes (completely unable or able to do housework) were less likely to be assessed as having rehabilitation potential.
- More likely to be completely unable to shop and less likely to shop without help
- Less likely to be completely unable to take their own medicine and slightly more likely to take their own medicine without help
- Twice as likely to be completely unable to walk than those not suitable for rehabilitation
- More likely to be able to bathe
- Less likely to have cognition problems than those not suitable for rehabilitation
- Slightly more likely to have behavioural problems than those not suitable for rehabilitation.

Implications for outcome measurement

The ACCNA and CENA trials showed how to build decision support tools into assessment systems and the refinements of decision support models have been examined in subsequent work in the national Access Points trials. Without a continuous client record, maintained as part of a larger client information system, the potential for routine outcome measurement is limited. This is because outcomes require measurement at different points in time so that changes can be described and linked to what is known about the goal of care and the services and interventions that may have a relationship to any changes that are detected.

There are routinely collectable measures that are predictive of likely outcomes and the development of an 'index of rehabilitation potential' is clearly feasible based on the relatively limited data available. The suggestion from the field that this factor might be incorporated into the system of priority rating reflects how the goals of community care are now becoming more proactive and moving beyond the provision of basic maintenance care. The selection of clients for more active interventions and then measuring them later on some of the same items to see what changed is an example of how an 'enablement' model can include routine outcome measurement.

In terms of building a more complex classification approach to outcome measurement, the goals in the ACCNA were relatively limited in number as they were based on those most relevant to the HACC program. The assessor was asked to record one area where assistance is required. These can be built into a classification at the first level where the goals of care are to:

- (1) Improve current level of function and independence after a recent acute illness/event
- (2) Improve current level of function and independence (other)
- (3) Maintain current level of function and independence
- (4) Reduce rate of decline in level of function and independence

The ACCNA design needed to be further refined in subsequent versions to accommodate priority rating for different service types and the prediction of rehabilitation potential. Other areas noted for development included using the ACCNA to explore unmet need on a regional basis and using it for re-assessment. This direction of further work would represent a significant step towards routine outcome measurement in community care.

7. NSW PADP Priority Rating and Capacity to Benefit (Aids and Appliances)

The purpose of the research was to propose a common state-wide approach to the assessment of applicants for PADP aids and equipment using standardised data elements and a priority rating system. The basis for developing a common person-centred assessment system for applications was the use of 'need' and 'capacity to benefit'.

'Need' was captured with a global measure of function, but function on its own was recognised as being insufficient and functional capabilities can vary over time. The design recognised this in developing more standardised ways of capturing the *context* of the application, and criteria for identifying people potentially disadvantaged by such an approach such as those with life limiting conditions or advanced age.

The project confirmed the anticipated difficulties of achieving a uniform approach, reflecting the complex decision making by PADP managers and PADP committees in approving applications. While full uniformity may not be possible, a common and more standardised system is clearly feasible. The results showed that the number of items in the adult assessment tool could be reduced while maintaining its usefulness as a decision-support tool. On that basis it was recommended that a common system for adult applications be implemented, based on the results of the project. (http://chsd.uow.edu.au/Publications/2005_pubs/padp_final_report.pdf)

The recommended tool should allow for the writing of narrative reports, which provide the necessary context for applications both for prescribers and PADP committees. The narrative elements were to be maintained, with some standardisation of the structure used. Consideration of whether a factor in priority rating should be a judgement about how long applicants can afford to wait for equipment, but how a suitable "weighting for waiting" could be applied was not part of the research.

Implications for outcome measurement

The results of the project showed a common approach across the system was feasible, but indicated the inherent difficulties in building a more uniform approach, especially for a priority rating tool. It is preferable to first implement a common assessment system using standard data elements, and allow it to operate for a reasonable period of time (one year was recommended) to allow the issues of priority rating based on capacity to benefit to be addressed empirically, using the considerable amount of data that can be collected, especially data from re-assessments.

A common assessment system using standard items will yield valuable data on the range of applicant needs and risks across settings, and analysis of an ongoing data set will improve the understanding of applicants' relative priority. Depending on the types of analyses conducted using the accumulated data from PADP applications, and given a systematic approach to R&D within the program, then useful reports, including on the relationships between allocation decisions and client outcomes, would be able to be generated to inform future policy decisions.

8. Post School Programs allocation model (2002-2010)

DADHC commissioned the Commonwealth Rehabilitation Service (CRS) in 2002 to assess post-school leavers who were already in, or applying to join, what was then the NSW ATLAS program. Schools (Special Support Teachers) completed the 9 item Functional Screen on each school leaver so that the results achieved with a short functional screen, and the results achieved with the full functional assessments undertaken by the CRS, could be compared.

The first major report on "ATLAS consumers and their prospects" was produced in 2002 and in 2003 the first assessments using the new tool were conducted. In 2006 ATLAS became Post School Programs including Transition to Work (TTW) and Community Participation (CP). Also in 2006 the Post School Programs Classification & Costing Study was conducted, leading to 4

funding bands for CP being introduced. From 2007 onwards the assessment tool has been used to determine eligibility for PSP and, if CP, to allocate the students to the CP funding bands.

The research questions in the work program were of relevance to program management as well as being of interest in and of themselves. The key questions were:

- Which measures of the person and their needs, e.g., age, sex, disability, strengths, barriers, self care functioning, domestic functioning, behavioural functioning, best predict the person's current and future capacity for work (with and without the recommended interventions) and/or the interventions and type of assistance that the person needs?
- How do the results achieved with a short functional screen (undertaken by schools) compare with the results of a full functional assessment (by the CRS)?

The research was also important because it tested if the functional hierarchy of Activities of Daily Living (ADLs) that was mainly used for the frail elderly population could also be used with younger people with disabilities. The results showed young people in the PSP acquire functional abilities in a fairly predictable order, and that the hierarchy of functional acquisition was predictable enough to support screening. That meant you can assume that, if a person can do ADLs acquired late, they can also do ADLs acquired early, thereby supporting short and targeted assessments rather than a comprehensive assessment.

A conclusion that can be drawn from the PSP work program is that a classification approach is both feasible and useful when applied to program management in disability and community care programs. This is the most sophisticated work done in client classification, at least in NSW, because the eight CP classes have been determined by reference to data on costs collected in an extensive costing study conducted with agencies providing services under the program. That means the classes are linked not only to the individual's level of need, but also in a predictable way to the cost of the program they are assigned to.

Another important lesson from this work was that an effective data collection could be used for classification and allocation purposes, but it required more room for the 'story' of the young person to be recorded in comment boxes. This extra information was particularly important for informing the appeals process and where allocation decisions were being made for young people at the margins between classes or funding bands.

Implications for outcome measurement

The body of work on Post School Programs (PSP) is substantial and illustrates the value of a consistent and planned development pathway. Classes of clients developed on the basis of a costing study give a much more powerful set of tools for program managers than do allocations based only on client characteristics.

The work in Post School Programs is about assessment, classification and allocation, but does not go on to consider outcomes as such. The standardising and routinising of the measures in these programs means it would be a relatively simple matter to use the same measures at a later time to check whether the young persons' skills or functional abilities had changed and whether this might be attributable to the programs they were using. However, the question of attribution in these types of programs will remain difficult because of the range of additional services and supports that are involved with young people with disabilities.

These PSP re-assessments do take place but are not systematically collected inside the CIS or other systems in order to be analysed and reported to the young people and their carers, the agencies or the program managers to inform them about the outcomes of the placements and levels of support they have been given.

It is important to note that one-off assessments are good to use to assign priority or in this case to determine a classification of the young people, but that this is not the same as measuring outcomes, which require subsequent measures be taken and change scores examined and analyses of other information (both client 'stories' and data on utilisation) to be included.

The linked series of contracts in one set of programs shows the value of a 'R&D' culture attached to a coherent body of work to develop routinely used tools. In this case in the yearly screening of a new cohort of young people, extended over a relatively long time period (seven years), where data could be collected and analysed, has led to the assessment tools and allocation processes being continually refined.

Subsequently the system developed in the work on PSP in disability in NSW was extended to a regional pilot program in Victoria called the Functional Assessment Tool Pilot to manage the transition of young people from school to work or community participation. That pilot showed that the tools could be used successfully in another jurisdiction and the assessment process could be tailored to produce more detailed and individualised reports.

9. 2007-2008 – SAFTE evaluation using ONI data

The NSW Sub Acute Fast Track Elderly (SAFTE) Care Program was a pilot program to target older people living in the community who are at risk of presenting to an Emergency Department (ED). It was based on the premise that by providing rapid response multi-disciplinary assessment and diagnostic services, together with a coordinated comprehensive package of care and support services (provided in collaboration with Community Options through ComPacks), that ED attendance and/or hospital admission can be prevented and/or delayed or shortened. A secondary premise was that the cost of the provision of these services would be equal to, or less than, the cost of the avoided ED and inpatient services.

SAFTE teams were able to respond to the health and care needs of clients through the provision of ComPacks (63% of clients received a package of services), nursing care (73%), physiotherapy (59%), occupational therapy (51%), equipment (50%), medication reviews (50%), referrals to a specialist (45%) and pathology services (28%).

The complexity of the clinical, functional and social needs of the client group required a coordinated approach to assessment and care planning and this was facilitated by the routine use of the ONI tools. The SAFTE program demonstrated that the partnership arrangement enabled client needs to be met in a comprehensive and coordinated manner and assisted in decision-making for longer-term care needs. Working in partnership was easier because of the common 'language' provided by the use of the ONI and this had benefits for those health and community care staff directly involved, as well as their teams more broadly. The benefits of using a tool such as the ONI were that staff could adopt a more holistic approach to identifying and meeting the needs of clients. It also reduced the burden on clients who were not required to 'repeat their story' to the numerous service providers who may be involved in providing them care.

The standardised assessment tool also assisted in ensuring the consistency of approach to demand management between sites, and allowed for improved comparability of data for the purposes of quality improvement in the targeting and delivery of the services. However the lack of interoperability of the data was a major issue as it limited its usefulness as a way of measuring outcomes for the purposes of the evaluation, requiring judgements to be made by care coordinators to be used as an alternative. This is a less controlled and objective form of information in the evaluation context, although it is a useful process of making evaluative judgements in a practical sense for the coordinators and agencies involved in the program.

Implications for outcome measurement

The complexity of the needs of the client group, and the interrelatedness of the clinical, functional and social needs, required a coordinated approach to assessment and care planning. The SAFTE program proved the value of using a standardised assessment tool such as the ONI, which addresses both health and community care needs. The modular design of the ONI and the use of its optional profiles to explore domains of need and risk in more depth, only where relevant to planning care for the client,

However, the '*inter-operability*' of the data was limited by the different electronic systems being used across health and community care. To use the data collected by ComPacks in the evaluation and as part of outcome measurement, the ONI data needed to be manually re-entered into a central repository before being able to be analysed for use in the evaluation.

Assuming that inter-operability will improve over time, and that electronic health records require community care domains to be included, then the capacity for using standardised data elements in assessments of clients at different points in time can generate 'change scores'. Change scores across selected key indicators like functional assessment, social and emotional well-being or social isolation scales can then be interpreted as outcome measures to evaluate the impact of interventions or care packages.

10. The ONI-N in the national Access Point pilot (2008-09)

This work involved two separate contracts in support of the national framework for community care assessment through the implementation of the ACCNA/ACCNA-R/ONI-N and CENA/CENA-R tools in the Community Care Access Centre for the Hunter Local Planning Area, one of the seven trials being conducted in the states and territories.

The projects provided two parts of the larger agenda of establishing and operating the NSW Access Point and feeding the lessons back at national level. The first part was the design of the assessment tool for the intake system for the Access Point (ONI-N) and the second was the analysis of the data that were generated by that system.

The final report and recommendations from the national ACCNA trials was the basis for building the ONI-N for NSW and two important decisions were taken at the beginning of this work program. One was to build the assessment system on the existing ADHC client information platform (CIS), and to do that in anticipation of the improved functionality in the next version, the CIS2.

The other key decision was to use the existing NSW Government's Human Services Network (HSNet) to enable electronic referrals. HSNet is a web-based secure client management and referral system linking seven human service portfolio agencies in NSW. By using HSNet, the Access Centre staff can electronically transfer data to service providers with some capacity to download the information into Client Management systems used by many NSW service providers. The transfer of inbound referral details to the service providers eliminates the need for care recipients to repeat their details and any service history to each provider.

The alternative to the NSW 'built-in' approach was to wait for the software to run the ACCNA-R, called the Community Care Access Support System (CCASS) which is a web application that contains interrelated functions and components including its own Customer Information System, Assessment Tool, workflow process and a facility linking Access Points to and from service providers. It was recognised that the CCASS system was likely to take some time to be built, would duplicate the functions available in other applications of this type and would be implemented at a cost to the future inter-operability of the larger ADHC and health client information systems.

The second contract was to analyse the data from the Access Point trial as part of an internal evaluation and development process for ADHC. It provided an initial description of the inbound

referrals to the NSW Access Point Demonstration Project and supplementary analyses looked at some specific characteristics of clients in the assessments of the inbound referrals. These analyses were to determine whether a simplified process of assessment could be designed for clients of high volume service types such as those seeking specific single services such as transport, domestic assistance or delivered meals.

The data extracted from the CIS (7,907 initial contacts and 1,997 that were not initial contacts) were provided in reports that were complex and because of this complexity, there was considerable time required for turning the exported data sets into data that could be analysed. This was because details about some inbound referrals and assessments were recorded several times. In practical terms, that involved understanding the structure of the extracted data and re-ordering that data to support the analysis and produce a useful series of tables and charts.

The data were able to describe some, but not all, of the key the characteristics of care recipients who were assessed and referred. The low completion rate of the functional profile is of interest to outcome measurement as change over time on these scores is relevant to understanding the impact of community care interventions on the HACC population. Comparisons with state and national figures for the functional profile scores would be useful, but were beyond the scope of the analysis in the project.

Given that the functional profile forms part of the HACC Minimum Data Set, the finding that half of the care recipients had incomplete profiles suggested there were errors in the way data were entered into the CIS, or errors in the data export function. These potential sources of error were expected to be easier to investigate and resolve in CIS2

The characteristics of inbound referrals requesting the most common single service types (transport, domestic assistance and meals), were looked at separately in order to understand whether a simplified process of assessment would be feasible and whether there were differences between those who did and did not have their requests met. Of the 6,493 clients requesting a single service, 3,507 (54%) were referred for the same single service that they requested, and 2,986 (46%) were referred for different services. The data indicated that there were very few differences between people in the group that received the range of services that they requested, and the people in the group that received a different set of services to those they requested.

The Access Point data indicated there is some scope for considering direct referral without more detailed assessment at the initial contact point, based on the initial request, and the evidence that more than half of such requests for referral are being met and there are high volumes: transport for client domestic assistance, delivered meals and home modifications.

Lower volume service requests that could also be considered for a simplified pathway because they are also likely to be met are Occupational Therapy and Podiatry (either home or centre-based). However, access to these two service types may be restricted by supply issues. Other service types with scope for direct referral (based on the initial request being met), were nursing care at home and case management both of which are service types where some level of more detailed assessment would be needed, rather than recommending direct referral.

Implications for outcome measurement

The NSW Access Point is an example of a 'social laboratory' in the field that provides a relatively controlled setting where standardised data for research and development in community care can be gathered and used for multiple purposes. The development of a continuous client record, and improved functionality and inter-operability in client information systems, will make various forms and levels of outcome measurement more feasible.

The "mapping" of intake assessment and referral pathways, processes and practices, including indicators and triggers for referral and managing priority and risk in community care services, are

all examples of work that can be progressed inside a bigger R&D program. Linking that work to the aim to develop a more integrated community care sector under state and national reforms will present opportunities to move the sector beyond measuring outputs and refining assessment frameworks to a system that is also capable of examining the impacts of its services on their users.

For example, the Access Point systems could be used to test the utility of the data elements most useful to trigger referrals for 'restorative' services for the HACC population. It is important to select a group of clients capable of achieving some level of change in functional abilities over time and where restoration of function is a realistic goal. By having basic information on the interventions provided, standardised re-assessments at a later point in time should allow outcome level judgements to be made, based on change scores in scales measuring functional ability and social and emotional well-being.

11. ONI-IAM – Intake Assessment Module for ADHC Regions including children with disabilities (2008-2009)

A literature review on community care assessment and prioritisation systems commissioned by DADHC (Alt Beatty Consulting, 2008) provided the basis for the trial of an assessment system tailored for the Departments Regional intake systems. This project developed an Intake Assessment Module with eight domains for use by DADHC's Regional Intake, Referral and Information (IRI) assessors.

This module was designed to link to a broader range of domains that comprise a broad and shallow assessment that is only completed when and if the circumstances warrant more detailed information being collected. The outcome of this project also included the software and relevant manuals that were used in the field trial. The tool was based on the ONI-N (Ongoing Needs Identification-NSW) tool used by DADHC in the HACC Access Point Demonstration Project in the Hunter Valley.

The work produced a shallow and broad assessment instrument for ADHC to trial in four of its Regions, and an Older Carers Project in Northern Region. There were four levels for the tool to be used. Level 1 was information only (callers are redirected), and Level 2 was the intake function. The remaining levels could be used at the discretion of the IRI worker or by a case manager or other appropriate staff to further assess needs.

The tool measured the functional ability of the person with a disability and captured any risks to that person in terms of their care situation. These two domains of needs and risks can derive a summary score called a Service Response Classification (SRC). The needs component is similar to the approach used by ADHC in its post-school programs. The algorithm that produces the Service Response Classification for adults is included in the ONI and is similar to that used by NSW Home Care to rank a client's priority for service. The algorithm for children was developed but required further development based on the collection and analysis of a larger data set.

In both adults and children, the SRC algorithm can be refined via analysis of the data collected at intake in order to calibrate the scores that best reflect ADHC policies. For example, if the data analysis finds that too many or too few people are being assigned to a particular classification, then the scoring criteria can be adjusted to decrease or increase the numbers assigned to that classification.

The SRC was considered as a summary score (a derived data item based on data that is routinely collected) and is an example of a decision support tool for assessors to develop the best plan of action for the person with a disability and/or their carer. The assessor, as the direct entry point contact, has the ability to consider all relevant information about the person and their

circumstances and therefore make the appropriate recommendations for action. The SRC is one part of the information that can be used in considering that recommendation.

The project was different to those conducted in the HACC program in that it developed and tested the useability of specific assessment questions for children and young people and included an approach for the assessment of children over 6 years of age. Although built on related work on a tool implemented to assess applicants for Carer Benefit (Child), further research and development was required to refine these questions and to develop a SRC algorithm that is directly relevant to ADHC programs and policies. The report recommended the tool be further developed in a way that is consistent with the implementation of the NSW Government's other child-related initiatives, particularly the "Keeping Them Safe" initiative.

Feedback from the trial sites was that, in general, the tool gave a good understanding of the person with disabilities and their care situation. However, IRI assessors found that the tool was too broad for the majority of situations and recommended that the tool be scaled back into a minimum set of domains. They also suggested modifications in terms of changes to questions and extra data items, some of which were incorporated during the course of the trial.

Assessors also found that the listing of DADHC-identified priority groups did not assist them. The importance of adequate training and support to implement a more standardised approach and build an understanding of the concepts behind the tool, were also noted.

Child functional profile items were developed and found acceptable in the trial of their useability. The algorithm for assessment has been outlined but a study collecting routine data needs to be done to work out how the data are best able to be used in the Regional Intake settings.

Implications for outcome measurement

In summary, the ONI-IAM project showed the potential to create a 'first generation' version of a set of client classifications that could be used consistently across programs. The use of routinely collected data elements also has the potential to generate a tailored set of outcome measures when the same data are collected at suitable transition points or when undertaking regular re-assessments.

12. Conclusions from the work of one research centre

A process of continuing and systematic collection, review and analysis should aim to refine a suite of data elements and measurement scales by analysing the data that is collected in routine practice. This is so that the relationships within the resulting data set can be analysed and investigated. Identifying those items that are most commonly used (and/or rarely used) and those that can best predict client and carer outcomes measured at a later time is one aim. Another aim is to reduce the burdens of data collection over time.

There is enough experience already accumulated within ADHC to confidently move towards more systematic outcome measurement. It needs to be systematically brought together rather than having important lessons left inside the various programs, their research projects and reports. The recommended suite of data elements that includes the potentially useful outcome measures derived from this review of ADHC projects, as well as items useful for organising service responses, is included in Appendix 2.

Implementation of a common approach to outcome measurement can realistically be described as part of the agency's continuing tool development processes, similar to what has occurred with the assessment approach used by Post School Programs. This recognises that there is an ongoing development role as demands on assessment and service systems change, as do the expectations of its users, both clients and staff.

13. Linking to related research and development activities

There are a number of key documents (apart from those prepared by one research centre) that are related to outcome measurement and these suggest a degree of continuity across a range of commissioned projects and their lessons. They are useful within and across the agency and the sector as a whole to strengthen the evidence base

It would be useful to consolidate these findings in one place so as to improve access to the details of the work done and provide wider access to the logic and methods used in each project and to make adding additional material relatively easy because it would be part of a wider body of evidence and help to turn research into practice

The rationale for supporting and linking a series of 'research into practice briefings' includes a number of assumptions:

- We know we are making progress when we can show we have measurable improvements in standardisation and in building a common approach in routine service monitoring systems
- It is best when improvements in outcome measurement are part of State and national systems – with support worker/clinician and agency buy-in – and ideally built into national Partnership Agreements, like for example, in the systems in rehabilitation and palliative care.
- Intake and assessment and priority rating systems are already in common use – for example in the Home and Community Care Functional Screen in the HACC Program MDS, but compared to the effort in reporting data, relatively little aggregation of the data and analysis of the information it contains has been done.
- There are good examples of evidence-building based on programs of research that are hosted on the various sponsors' websites – like evidence on effective on effective interventions for promoting child well-being in Victoria, evidence on meeting the needs of carers in the Commonwealth Respite for Carers Program, measuring outcomes in dementia, community care assessment and wellness approaches in Victoria and WA.
- Measuring whether knowledge transfer has actually taken place is a continuing challenge and there is little evidence to fall back on in this area (i.e. evidence of the impact of evidence!).
- Traditional publication output is necessary in order to build up the broader evidence base, but not sufficient to build up a system in community based care and disability services where evidence has to be made more easily accessible.
- Web-based systems for handling this level of information exchange are evolving rapidly.

Many research and consultancy groups have put together good quality evidence to help ADHC to build and improve decision support tools and to back up the various client information systems. Making better tools that enable initial assessments to trigger referrals for deeper or more specialised assessment, to assist care planning for basic support and more restorative or enabling community care services is an important step towards better functioning client information systems. Beyond the initial steps we have described here the aim is to support a better intake system so that it can feed into an ongoing client record and allow subsequent assessments to tell program managers more about what outcomes the service efforts have achieved.

About the Centre for Health Service Development

The Centre for Health Service Development (CHSD) was established in 1993 and is a self-funded research and development centre of the Sydney Business School and is one of the University of Wollongong's Research Strengths (<http://chsd.uow.edu.au/>). It aims to improve the management and provision of health and community services in Australia by achieving greater equity in resource

distribution, fairer access to services, better continuity within and across the health and community care sectors, and using evidence to assist management decision-making.

To achieve these aims the CHSD has created a set of ongoing service development programs and also carries out short and long term projects guided by its research themes: client classification across settings; health and community care financing; care coordination and integration; outcome measurement; service delivery and organisation; and tools to assist management decision-making.

The particular projects and programs that have informed this submission include our research on the assessment of need and outcome measurement in community care and disability programs, the evaluation of the national 'Encouraging Best Practice in Residential Aged Care Program', various evaluations of hospital avoidance pilots, and our information management and service and sector development programs:

The **Australian Centre for Clinical Terminology and Information** (<http://chsd.uow.edu.au/accti/>) has expertise in information strategies to support e-health initiatives with consistent, current and reliable clinical documentation.

The **National Casemix and Classification Centre** (<http://nccc.uow.edu.au/index.html>) is responsible for the development of the Australian Refined Diagnosis Related Group (AR-DRG) Classification System and is funded by the Australian Department of Health and Ageing to promote and support the use of acute care health classifications linked to funding.

The **Australasian Rehabilitation Outcomes Centre** (<http://chsd.uow.edu.au/aroc/>) supports a national benchmarking system to improve clinical rehabilitation outcomes in both the public and private sectors by the systematic collection of outcomes information in both inpatient and ambulatory settings. It distributes clinical and management information to clinical units as well as annual reports that summarise the Australasian data and provides education, training and certification in the use of outcome measures.

The **Palliative Care Outcomes Collaboration** (<http://chsd.uow.edu.au/pcoc/>) is a voluntary quality initiative to assist palliative care service providers to improve practice and meet the "Standards for Providing Quality Palliative Care for All Australians". Its aim is to develop and support a national benchmarking system that will contribute to improved palliative care outcomes. It is a collaboration between four academic centres and is divided into four geographic zones for the purpose of engaging across Australia with palliative care service providers.

The **Australian Health Outcomes Collaboration** (AHOC) disseminates information about health outcomes research, provides advice on the selection of measures for health outcomes as well as education and training. It distributes measures and instruments used in health outcomes assessment. <http://chsd.uow.edu.au/ahoc/>

The **Australasian Occupational Science Centre** (AOSC) is located at the University's Shoalhaven Campus, in Nowra and provides community education programs and conducts research projects on the relationship between health and purposeful occupation and public health policy. <http://shoalhaven.uow.edu.au/aosc/>

Appendix 2: Data to support outcome measurement

Information about the recommended data elements

The following table provides a list of the data elements suggested for use in community care information systems. This list is not exhaustive, i.e., additional service and program specific information such as specialised or standardised assessment tools (for example for measuring social isolation) would need to be added in over time.

This might be done at the program level or by agency level managers, to facilitate their care planning and service responses. This list should be considered as a common base for information collection and data sharing concerning outcomes, and within the list a preliminary set of the initial 'best bet' outcome measures are highlighted in **BOLD AND CAPITALISED**. These items could be used at a point of re-assessment to measure change.

There are 2 broad types of information collected – assessment information (relevant for outcomes) and information for service response (ISR highlighted in the second column) that is necessary to organise a service response. The table lists the data elements, and responses and codes, and which of the recent ADHC projects (the Post School Program, ONI-N and ONI-IAM) in which they were used.

Each of the data elements that are listed below provides a useful piece of information about a person. This information can be put together to provide a more rounded picture about the person, their situation, and their needs. Knowing that a person is 1.8m tall says something, but if we also know that the person weighs 140 kg or 50 kg, then that tells us more about them, like the way that a body mass index is useful in measuring physical fitness. Knowing their functional screen score is helpful, but additional linked information on their carer status or a social isolation score, tells us much more.

Bits of information can also be combined to help predict something about the person. Giving scores to responses to the items in the functional profile, and combining them in an algorithm to provide a numerical score, can provide a summarised index of a person's functional abilities, strengths and vulnerabilities. These algorithms can be validated by large scale studies such as those that have been carried for Home Care and Post School Programs.

There are examples of the elements for validated algorithms in the list:

- The HACC Adult Functional Screen
- Carer status
- The 20 point Modified Barthel Index (Collins scoring)
- Kessler Psychological Distress Scale (K10)

These algorithms are used to provide assessors and service providers with guidance about what actions to take, for example, The Kessler Scale suggests the risk level of anxiety or depressive disorders, e.g., a score under 15 indicates low risk and no need for action, while a score over 30 indicates a need for a specialist mental health referral. The final decision, however, should be in the hands of the assessor.

The ONI-IAM trial developed a list of data elements for use as a functional assessment for children. The algorithm to use these data elements to provide a functional score for a child is an example of where the logic has been tested but additional work still needs to be carried out so that the relationships between the items can be analysed, further developed and empirically tested.

There is clearly potential to use other combinations of data elements to help an assessor decide the appropriate service response for a person. For example, the ACCNA Field trial used some derived data items and algorithms to suggest to assessors the referrals for people with particular identified needs. An example was that an assessor should consider referring a person for a cognitive assessment if:

- If the person cannot take their own medicine or handle their own money (Questions 4 and 5 in the Adult Functional Screen) and the person has no physical disabilities or problems with English literacy that may account for the person not being independent on these items
OR
- If there is evidence of memory problems or confusion (Question 8 in the Adult Functional Screen)
OR
- If there is medical diagnosis of dementia in Health Conditions Profile AND has not been recently assessed by a doctor

Another example to illustrate the use of a combination of data items is in the analysis of the data collected in the ACCNA trial to identify a number of characteristics of people where a referral for a rehabilitation assessment can be confidently recommended as part of a more complex service response like that being promoted in the Active Service Model in Victoria.

The characteristics of these people with rehabilitation potential were:

- More likely to need help with housework. Those at the extremes (completely unable or able to do housework) were less likely to be assessed as having rehabilitation potential.
- More likely to be completely unable to shop and less likely to shop without help
- Less likely to be completely unable to take their own medicine and slightly more likely to take their own medicine without help
- Twice as likely to be completely unable to walk than those not suitable for rehabilitation
- More likely to be able to bathe
- Less likely to have cognition problems than those not suitable for rehabilitation
- Slightly more likely to have behavioural problems than those not suitable for rehabilitation.

The development of such an 'index of rehabilitation potential' was beyond the scope of the ACCNA trial at the time that it was carried out in 2007-2008, but the data suggested that further refinement would be feasible and could be part of a longer term research and development agenda. That agenda would use a data item pool inside the client information system (and/or built into agency-level client management systems in use in the non-government sector) and data collected in routine practice would then be aggregated and analysed to explore the relationships between the items.

These more complex analyses could be guided by well-established techniques such as Computer Adaptive Testing based item response theory, which is the current best practice framework that has led to the development of sophisticated systems that are useful for assessors. (http://en.wikipedia.org/wiki/Item_response_theory).

Computer Adaptive Testing (CAT)

Computer Adaptive Testing (CAT) uses a computer algorithm to pre-select the items that will be administered to a specific client based on responses to previous items. Boston University has developed this method in its Activity Measure for Post Acute Care™ (AM-PAC) (see Jette et al 2007 and the instruction manual at <http://www.creare.com/home.html>).

CAT-based instruments have the following advantages:

- They reduce test burden while increasing test precision because test items are selected to match the patient's functional ability level.
- Patients are not required to respond to irrelevant test items.
- It is easy to integrate assessment into work flows.
- They promote efficient and reliable data entry, analysis and management. AM-PAC data, along with patient data (age, gender, diagnosis, time since onset, surgical status, severity and insurance), are entered and stored in a database on the local computer or on a server.
- It only takes two minutes to complete each domain.
- They can include patient satisfaction questions.

Jette et al (2007) have evaluated the system in a study on the Basic Mobility and Daily Activity scales and have explained the somewhat complicated concepts involved in the following way:

“This method of patient assessment uses a computer to administer test items to patients and is adaptive in the sense that each “test” is tailored to the unique level of each patient. Each person who takes an adaptive test is taking a different version of the test because the items are administered on the basis of the patient’s previous responses.

By avoiding the administration of a large number of questionnaire items, by selecting only those questions from a large “item bank” that provide the maximum amount of information based on a person’s responses to previous questions, CAT approaches allow for the rapid collection of accurate outcome information that can feasibly be implemented in busy clinical settings as well as in research settings.

A CAT is programmed to first present an item from the mid-range of a predefined item bank of outcome questions and then directs subsequent questions to the patient’s most appropriate level based on his or her previous responses. By having comprehensive item banks available for each outcome domain of interest, the CAT algorithm selects only the items that are needed to provide a score estimate based on a predetermined number of items or a predetermined level of measurement precision. This allows for fewer items to be administered to each patient while gaining accurate information regarding an individual’s placement along an outcome continuum.

The development of comprehensive and methodologically sound item banks for each outcome of interest is a prerequisite to the development of psychometrically adequate CAT platforms that have clinical or research utility.” (p.386)

While the AM-PAC tool is technically quite complex, the basic concepts involved are similar to the modular system of assessment developed in Australian community care sector in the work on the ACCNA and the ADHC version of the ONI-N that has implemented in the Hunter Access Point.

The recommended item bank (following section) has been refined as a result of reviewing the range of relevant ADHC-based outcome measurement work. It contains a range of useful outcome measures and could be supplemented with additional scales, for example, standardised scales such as those that might be chosen to capture the outcomes dimension of client or carer social isolation.

Starting with an item bank, then capturing sufficient data in routine practice to support detailed analyses, and then refining the way the items are then recommended to be used in practice, is an example of how a technical method such as CAT might be applied in an environment such as a client information system.

SNOMED-CT

The Australian Government has endorsed SNOMED-CT as the standard clinical terminology for all health domains in Australia. This includes the domain of community care. SNOMED-CT is an international collection of health and medical terminology including symptoms, diseases, events, social contexts, assessment and therapy regimes and surgical interventions. It provides a technical and reference standard allowing the sharing of information between different information systems. This enables clinical and care practitioners users to exchange and share information without the need to recode, reinterpret or translate records.

The use of an underlying SNOMED-CT terminology enables users to understand precisely what is meant when information is sent or received. Different practitioners, using different information systems at each end will be able to communicate effectively, co-ordinating their data, referrals and care for clients. That is, SNOMED CT allows all practitioners to share any language where they share the care delivery.

As SNOMED-CT is implemented into health and client information systems, it will mitigate against the potential miscommunication between various and different client information systems. Any new information systems using the underlying SNOMED-CT terminology will be optimally placed to participate in information exchange effectively.

An on-line browser to search the SNOMED items is available at <http://snomed.dataline.co.uk> .

Goal Attainment Scaling

Goal Attainment Scaling (GAS) has a long history (from the 1960s) in community mental health. More recently, in the rehabilitation literature, GAS has been reported as offering a number of potential advantages as an outcome measure for people with complex disabilities. It has a rapidly expanding literature, offers flexibility across the domains of impairment, disability and participation, and “there is growing interest from clinicians who, frustrated by the limitations of standardized scales, are starting to take a broader view of outcome assessment.” (Turner-Stokes et al. 2009, p.2).

GAS provides a quantitative assessment of goal attainment and also uses qualitative information about the person's own priority goals and their relative importance, and in that way is ‘client-centred’ in the sense that the goals are negotiated with the client as part of a care plan. “The process of goal-setting and rating supports dialogue between the patient and their treating team, and offers an additional opportunity to negotiate mutually agreed expectations for outcome. However, clinicians require sufficient knowledge, training and experience to support patients to set realistic goals.” (Turner-Stokes et al. 2009, p.1)

The method was discussed in agency-level consultations where case managers pointed out that its relative complexity, even in its simplified forms, could get in the way of a more sensitive negotiation about client-focussed goals and whether they have been attained. This implies that useful tools will require training and support function when introducing them into the community care sector.

Table 2 Recommended data elements

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
Assessment Purpose					
ASSESSMENT TYPE		Initial	X		
		Reassessment			
Assessment Purpose		Text	X		
Description of problem		Text	X		
Other Issues		Text	X		
Contact reasons					
Time	X	Auto-time	X		X
Date	X	Auto-date	X	X	X
Type of contact	X	Inbound phone	X	X	X
		Fax			
		Letter			
		Email			
		ReferralLink			
		In person			
		Other			
Why has caller contacted this service?		Text	X		
Information Only	X	Yes	X		
		No			
Information provided	X	Text			X
Caller Details	X	Text			X
Notes	X	Text			X
Record Services Requested		Domestic assistance	X	X	X
		Social support			
		Nursing care			
		Allied health care			
		Personal care			
		Centre-based day care			
		Meals			
		Other food services			
		Own home respite			
		Centre-based respite/respite homes			
		Host family respite/peer support respite			
		Flexible respite			
		Other respite			
		Open employment			
		Supported employment			
		Targeted support			
		Advocacy, information and alternative forms of communication			
		Information/referral			
		Combined information/advocacy			
		Mutual support/self-help groups			
		Alternative formats of communication			
		Assessment			
		Home maintenance			
		Home modification			
		Provision of goods and equipment			
		Formal linen service			
		Transport			
		In-home accommodation support			
		Alternative family placement			
		Other accommodation support			
		Early childhood intervention			

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
		Other community support			
		Learning and life skills development			
		Recreation/holiday programs			
		Other community access			
		Counselling/support, information and advocacy (person needing assistance)			
		Counselling/support, information and advocacy (Primary carer)			
		Case management support			
		Client care coordination			
		Case management			
		Vocational training			
		Family Support			
		Day activity support			
		Community participation			
		Transition to Work			
		Supported employment			
		Physiotherapy – assess & treat problems related to movement & posture			
		Walking & moving Around			
		Carrying, Moving & Handling			
		Fine Motor Skills			
		Gross Motor Skills			
		Occupational Therapy - develop and maintain an individuals functional skills			
		Mobility Assessment			
		Access Issues			
		Physical Management			
		Mobility Issues			
		Positioning			
		Equipment			
		Environmental Modifications			
		Seating			
		Using Transport			
		Speech Pathology –			
		Non-Verbal Communication (e.g. sign, gestures, pictures & behaviours)			
		Verbal Communication (egg. sounds, words & sentences)			
		Understanding (e.g. comprehension & following instructions)			
		Swallowing & Feeding			
		Behaviour Intervention – individual & alternative skills to address challenging behaviours (behaviour that interferes with community acceptance or lifestyle)			
		Where: Home; School; Other			
		Behaviour Type:			
		Tantrums			
		Self Injury			
		Offending Behaviours			
		Physical Aggression			
		Sexualised Behaviours			
		Verbal Aggression			
		Prevent Risky Behaviour			
		Other			
Comments		Text	X	X	X
WHAT WERE THE KEY CIRCUMSTANCES TRIGGERING CONTACT?		Hospital discharge	X		X
		Recent diagnosis			
		Falls			
		Acute medical condition			
		Carer burden			
		Concern about increasing frailty			
		Other			
What do you hope will change if		Text	X	X	X

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
the person is able to receive these services?					
Comments		Text	X	X	X
How long has person experienced this problem?		Text	X		X
Assessor, record codes		Recent diagnosis	X	X	X
		Gradual increase in needs over time			
		Long term disability			
		Other			
WHAT DOES THE CALLER EXPECT THE OUTCOME TO BE?		Text	X	X	X
ASSISTANCE IS REQUIRED TO:		Improve current level of function and independence after a recent acute illness/event	X	X	X
		Improve current level of function and independence (other)			
		Maintain current level of function and independence			
		Reduce rate of decline in level of function and independence			

Referral Source

Referral Source	X	(refer to MDS)	X		X
Referrer First Name	X	Text	X		X
Referrer Second Name	X	Text	X	X	X
Organisation	X	Text	X		X
Referrer Position	X	Text			X
Postal Address	X	Text	X		X
Telephone	X	Text	X		X
Fax	X	Text	X		X
Email address	X	Text	X	X	X
Assistance is required to		Text	X		X
Consent provided	X	Yes	X	X	X
		No			
Date of consent	X	Date	X	X	X
Authority of Consent	X	Text	X		X
Consent witness	X	Text	X		X
Consent comments	X	Text	X		X

GP/Service usage

Is person currently receiving services?	X	Yes	X	X	X
		No			
		Not sure			
Agency	X	Text	X		X
Service type	X	Alternate Therapists	X		X
		Aged Care			
		Alcohol and drug			
		Community health			
		Counselling			
		Dental care			
		Disability			
		Emergency accommodation			
		Family planning			
		Home care			
		Hospital inpatient			
		Hospital outpatient			
		Hospital emergency			

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
		Maternal and child health			
		Medical (GP)			
		Medical (specialist)			
		Men's health			
		Mental health			
		Palliative care			
		Rehabilitation			
		Residential Aged Care			
		Respite care			
		Self help groups			
		Sexual health			
		Women's health			
		Youth services.			
		Other			
Service Description	X	Text	X		X
Service Comments	X	Text	X		X
Comments	X	Text	X		X
GP details	X	Contact info	X		X
Registration & Demographic Information					
Type of Address	X	Text	X	X	X
Street number	X	Text	X	X	X
Street name	X	Text	X	X	X
Suburb/locality	X	Text	X	X	X
State	X	State list	X	X	X
Phone type	X	Text	X	X	X
Phone number	X	Text	X	X	X
Preferred phone flag	X	Yes	X	X	X
		No			
Message flag	X	Yes	X	X	X
		No			
Email	X	Text	X	X	X
Contact Instructions	X	Text	X	X	X
Contact Warnings	X	Text			X
Born in Australia	X	Yes	X	X	X
		No			
If Yes, ATSI status	X	ABS list	X	X	X
If ATSI, what is skin/tribal name?	X	Text	X		X
If No to Australia as COB, what is country of birth	X	ABS list	X	X	X
If Yes to Australia as COB, does person have CALD background or has CALD background, what is ethnicity of person?	X	YesNo	X		X
What is religion of person?	X	Text	X		X
Main language spoken at home	X	ABS list	X	X	X
Interpreter required	X	Yes	X	X	X
		No			
Preferred sex of interpreter	X	No preference	X	X	X
		Male			
		Female			
Preferred language (if not spoken English)	X	ABS list	X		X
Accommodation					
What type of accommodation does the person live in?	X	Refer to MDS	X	X	X
Does the person live alone?	X	Yes	X		X

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
		No			
If person does not live alone, whom do they live with?	X	Lives with family Lives with others	X		X
Comments	X	Text	X		X
Are there concerns about the living arrangements of the person?	X	Yes No Not sure	X		X
Comments	X	Text	X		X
Insurance					
Insurance Status	X	None Private health insurance – basic cover only Private health insurance – including auxiliary cover for private dental and allied health services Motor vehicle accident insurance Workers compensation Other 3rd party Ambulance fund	X		
Is there any evidence of previous difficulties between the person and health and community care providers?	X	Yes No Not sure	X		
Comments	X	Text	X		
Adult Functional Profile					
CAN YOU DO HOUSEWORK ...		Without help (can clean floors etc)? With some help (can do light housework but need help with heavy housework)? Or are you completely unable to do housework?	X	X	X
CAN YOU GET TO PLACES OUT OF WALKING DISTANCE ...		Without help (can drive your own car, or travel alone on buses or taxis)? With some help (need someone to help you or go with you when travelling)? Or are you completely unable to travel unless emergency arrangements are made for a specialised vehicle like an ambulance?	X	X	X
CAN YOU GO OUT FOR SHOPPING FOR GROCERIES OR CLOTHES (ASSUMING YOU HAVE TRANSPORTATION)...		Without help (taking care of all shopping needs yourself)? With some help (need someone to go with you on all shopping trips)? Or are you completely unable to do any shopping?	X	X	X
CAN YOU TAKE YOUR OWN MEDICINE ...		Without help (in the right doses at the right time)? With some help (able to take medication if someone prepares it for you and/or reminds you to take it)? Or are you completely unable to take your own medicines?	X	X	X
IF NOT WITHOUT HELP, IS REASON		Physical Cognitive Both	X		X
CAN YOU HANDLE YOUR OWN MONEY ...		Without help (write cheques, pay bills etc)? With some help (manage day-to-day buying but need help with managing your chequebook and paying your bills)? Or are you completely unable to handle money?	X	X	X

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
IF NOT WITHOUT HELP, IS REASON		Physical Cognitive Both	X		X
CAN YOU WALK ...		Without help (except for a cane or similar)? With some help from a person or with the use of a walker, or crutches etc Or are you completely unable to walk?	X	X	X
CAN YOU TAKE A BATH OR SHOWER...		Without help? With some help (e.g., need help getting into or out of the bath)? Or are you completely unable to bathe yourself?	X	X	X
These 7 questions are qualified by					
IF THE PERSON HAS DIFFICULTY, WHO HELPS THEM?		No-one Carer Service provider Other	X		X
(AND) To what extent is this need met?		N/A - no need Fully met partially met Completely unmet	X		X
DOES THE PERSON HAVE ANY MEMORY PROBLEMS OR GET CONFUSED?		Yes No	X	X	X
DOES THE PERSON HAVE BEHAVIOURAL PROBLEMS (E.G. AGGRESSION, WANDERING OR AGITATION)?		Yes No	X	X	X
Comments		Text	X	X	X
The 20 point Modified Barthel Index (Collins scoring)					
BOWELS		Incontinent (or needs to be given enema) Occasional accident (once/week) Continent		X	
BLADDER		Incontinent, or catheterised and unable to manage Occasional accident (max. once per 24 hours) Continent (for over 7 days)		X	
GROOMING		Needs help with personal care Independent face/hair/teeth/shaving		X	
TOILET USE		Dependent Needs some help, but can do something alone. Independent (on and off, dressing, wiping). Should be able to reach toilet/commode, undress sufficiently, clean self, dress and leave.		X	
FEEDING		Unable Needs help cutting, spreading butter etc. Independent (food provided in reach). Able to eat any normal food (not only soft food). Food cooked and served by others. But not cut up.		X	

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
TRANSFER (FROM BED TO CHAIR AND BACK)		Unable - no sitting balance Major help (one or two people, physical), can sit. Minor help (verbal or physical) Independent		X	
MOBILITY		Immobile Wheelchair independent including corners etc. Walks with help of one person (verbal or physical) Independent (but may use any aid, e.g. stick)		X	
DRESSING		Dependent Needs help, but can do about half unaided Independent (including buttons, zips, laces, etc.)		X	
STAIRS		Dependent Needs help, but can do about half unaided Independent (including buttons, zips, laces, etc.)		X	
BATHING (OR SHOWERING)		Unable Needs help (verbal, physical, carrying aid) Independent up and down		X	

Child Functional Profile

THE CHILD'S ABILITY TO DO EVERYDAY TASKS (E.G. EATING, BATHING, TALKING AND SOCIAL INTERACTION ETC) IS		Relatively Stable ((i.e. the child is likely to require the same level of assistance in the future) Improving over time (i.e. the child is likely to require less help in the future) Becoming worse over time (i.e. the child is likely to require more assistance in the future) Not sure/I don't know			X
Comments	AJ				X
DOES NAME (YOUR CHILD) NEED SPECIAL CARE SUCH AS THERAPY OR MEDICINES OR SPECIAL AIDS AND EQUIPMENT? IF YES, COMPLETE SPECIAL NEEDS		Yes No Not sure			X
ARE THE CHILD'S SLEEPING PATTERNS SIMILAR TO OTHER CHILDREN OF THE SAME AGE?		Yes No Not sure			X
DOES (NAME) YOUR CHILD GET MORE IRRITABLE THAN OTHER CHILDREN OF THE SAME AGE?		Yes No Not sure			X
IF YES - ASSESSOR , GO TO BEHAVIOUR SLEEP SECTION					
DOES YOUR CHILD WEAR NAPPIES DURING THE DAY?		Yes No Not sure			X
IF YES - ASSESSOR , GO TO TOILETING SECTION					
DOES THE CHILD HAVE MORE PROBLEMS DOING EVERYDAY TASKS (E.G. EATING, GROOMING, BATHING, USING THE TOILET) THAN OTHER CHILDREN OF THE SAME AGE?		Yes No Not sure			X

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
IF YES, COMPLETE EVERYDAY TASKS					
DOES THE CHILD HAVE MORE BEHAVIOUR PROBLEMS THAN OTHER CHILDREN OF THE SAME AGE		Yes No Not sure			X
IF, YES, COMPLETE BEHAVIOUR SECTION					
SPECIAL NEEDS					
DO YOU PREPARE OR ADMINISTER MEDICATIONS RELATED TO YOUR CHILD'S MEDICAL CONDITION?		Less than 30 minutes a day 30 minutes or more a day			X
DO YOU SUPERVISE, REMIND, PROMPT OR PROVIDE PHYSICAL ASSISTANCE WITH EXERCISES, THERAPIES, INTERVENTIONS (PHYSICAL, PSYCHOLOGICAL OR EMOTIONAL), BLOOD TESTING OR AIDS, SPLINTS, GARMENTS OR OTHER EQUIPMENT?		Less than five hours a week More than five hours a week			X
DO YOU MANAGE ANY WOUNDS OR DRESSINGS FOR YOUR CHILD?		Less than 30 min per day 30-60 min per day 1-2 hours per day More than 2 hours per day			X
DO YOU PROVIDE PHYSICAL ASSISTANCE TO TURN OR POSITION YOUR CHILD BECAUSE HE/SHE IS UNABLE TO DO SO INDEPENDENTLY?		During the day Less than daily Once or twice a day Three or more times a day During the night (i.e. 10pm to 6am) Less than nightly Once a night Two or more times a night			X
DO YOU PROVIDE CARE AND/OR INTERVENTIONS FOR POORLY CONTROLLED MAJOR SEIZURES?		Less than monthly Once or twice a month Three or more times a month			X
DO YOU PEG FEED OR USE A FEEDING TUBE TO FEED YOUR CHILD?		Less than daily Once or twice a day Three or more times a day, or continuous			X
DOES YOUR CHILD USE ANY OF THE FOLLOWING TO AID BREATHING?		a ventilator (mechanically assisted breathing device) a tracheotomy oxygen CPAP/BiPAP			X
DO YOU PROVIDE TPN (TOTAL PARENTERAL NUTRITION) FOR YOUR CHILD?		Yes No			X
DO YOU DO POSTURAL DRAINAGE FOR YOUR CHILD?		During the day Less than daily Once or twice a day Three or more times a day During the night (i.e. 10pm to 6am) Less than nightly Once a night Two or more times a night			X
DO YOU DO SUCTIONING (E.G. TO CLEAR THE AIRWAYS OF MUCUS OR SALIVA) FOR YOUR CHILD?		During the day Less than daily Once or twice a day Three or more times a day During the night (i.e. 10pm to 6am)			X

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		Less than nightly			
		Once a night			
		Two or more times a night			
DO YOU PHYSICALLY ASSIST OR POSITION YOUR CHILD'S JAW TO HELP WITH CHEWING OR SWALLOWING?		Less than daily			X
		Once or twice a day			
		Three or more times a day			
DO YOU PROVIDE STOMA CARE (E.G. COLOSTOMY, ILEOSTOMY) FOR YOUR CHILD?		Less than daily			X
		Once or twice a day			
		Three or more times a day			
DOES YOUR CHILD RECEIVE DIALYSIS?		At your home			X
		In a hospital clinic/dialysis centre			
SLEEP AND IRRITATION					
DOES YOUR CHILD HAVE EXTREME DIFFICULTY SETTLING BEFORE GOING TO SLEEP AT NIGHT (E.G. IT USUALLY TAKES MORE THAN AN HOUR BEFORE YOUR CHILD IS SETTLED AT NIGHT)?		My child never has difficulty settling before going to sleep at night My child rarely has difficulty settling before going to sleep at night My child sometimes has difficulty settling before going to sleep at night My child regularly (almost every night) has difficulty settling before going to sleep at night			X
DOES YOUR CHILD HAVE EXTREMELY DISRUPTED SLEEP AT NIGHT (E.G. YOUR CHILD WAKES UP MULTIPLE TIMES DURING THE NIGHT, HAS NIGHTMARES ETC)?		My child never has disrupted sleep at night My child rarely has disrupted sleep at night My child sometimes has disrupted sleep at night My child regularly (i.e. almost every night) has disrupted sleep			X
DOES YOUR CHILD DISPLAY BEHAVIOURS ASSOCIATED WITH EXTREME IRRITABILITY (E.G. CRIES PERSISTENTLY AND EXCESSIVELY, IS NOT ABLE TO BE SETTLED OR CONSOLED ETC)?		My child does not display irritable behaviours My child rarely displays irritable behaviours My child sometimes displays irritable behaviours My child regularly displays irritable behaviours			X
COGNITION					
PLEASE INDICATE WHETHER YOUR CHILD'S SPEECH AND LANGUAGE ABILITIES ARE SIMILAR TO OTHER CHILDREN OF THE SAME AGE:		My child's speech and language abilities are similar to other children of the same age My child's speech and language abilities are less than other children of the same age Please indicate how your child usually communicates: My child can talk but not as well as other children of the same age My child can talk but can only be understood by me or others who have been trained to interpret my child's speech and language My child cannot talk but can communicate their needs and wants in other ways (e.g., pictures, gestures, grunts, facial expressions or crying) My child cannot talk but can communicate their needs and wants in other ways (e.g., signing, pictures, gestures, grunts, facial expressions or crying) but only to me or others who have been trained to interpret my child's ways of communicating My child cannot communicate their needs and wants			X
PLEASE INDICATE WHETHER YOUR CHILD'S INTELLECTUAL ABILITIES (E.G. MEMORY, PROBLEM SOLVING)		My child has intellectual abilities similar to other children of the same age My child's intellectual abilities are less than			X

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ARE SIMILAR TO OTHER CHILDREN OF THE SAME AGE:		other children of the same age. Please indicate the level of prompting or supervision that your child requires to complete simple daily activities:			
		My child requires prompting (repetition, reminders) some of the time to complete simple daily activities			
		My child requires prompting most of the time to complete simple daily activities			
		My child requires constant one-to-one direction to complete simple daily activities			
PLEASE INDICATE HOW YOUR CHILD INTERACTS WITH OTHER CHILDREN OF A SIMILAR AGE:		My child interacts with other children in the same way as other children			X
		My child does not interact with other children in the same way as other children. Please indicate how your child interacts with other children:			
		My child requires occasional assistance from an adult to resolve problems/conflicts or to communicate with other children			
		My child interacts with other children appropriately with some coaxing/prompting, but requires adult supervision			
		My child needs a helper to initiate interactions and prevent and resolve conflicts			
		My child is not able to interact with other children			
OVERT BEHAVIOUR					
ASSESSOR, DO NOT READ OUT THE FOLLOWING LIST. INSTEAD, USE IT AS A PROMPT IN THE CONVERSATION. TICK THE RELEVANT BOX/AS AS ISSUES ARE IDENTIFIED.		Frequency			
WANDERS AND/OR ABSCONDS		Never happens			X
VERBALLY DISRUPTIVE OR NOISY		Rarely happens			
PHYSICAL AGGRESSION - HARMS OTHERS USING PHYSICAL CONDUCT SUCH AS HITTING, PUSHING, KICKING OR BITING		Happens sometimes			
EXTREME EMOTIONAL DISTRESS SHOWN BY, FOR EXAMPLE, INTENSE CRYING OR SCREAMING OR EMOTIONAL WITHDRAWAL OR ANXIETY OR INTENSE FEAR.		Happens much or all of the time			
BEHAVIOURS OTHER PEOPLE THINK ARE BIZARRE OR UNUSUAL. THIS MAY INCLUDE ODD RITUALS, NONSENSICAL REPETITIVE BEHAVIOURS AND/OR BEHAVIOURS THAT INDICATE THAT THE CHILD IS OUT OF TOUCH WITH REALITY.					
HIGH-RISK AND RECKLESS BEHAVIOUR, DANGEROUS TO HIMSELF/HERSELF OR OTHERS. AS A CONSEQUENCE, REQUIRES SUPERVISION AND ACTIONS SUCH AS LOCKING GATES, DOORS AND WINDOWS TO PREVENT THESE					

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BEHAVIOURS. SELF-HARM BEHAVIOURS (INTENTIONAL OR UNINTENTIONAL) SEXUALLY INAPPROPRIATE BEHAVIOUR SUCH AS EXPOSING HIS/HER BODY INAPPROPRIATELY TO OTHERS AND USING SEXUALLY INAPPROPRIATE VERBAL COMMUNICATION. SELF CARE DOMAIN					
DOES YOUR CHILD USE A SPOON, FORK OR CUP?		My child feeds himself/herself and does not require me to provide any help My child requires me to provide supervision with or without a small amount of physical help with feeding My child requires me to provide considerable physical help with feeding My child is bottle fed OR is completely dependent and requires me to feed him/her			X
DOES YOUR CHILD DO EVERYDAY GROOMING TASKS (E.G. BRUSH TEETH, BRUSH/COMB HAIR, WASH AND RINSE HANDS AND FACE)?		My child grooms himself/herself and does not require me to provide any help My child requires me to provide supervision with or without a small amount of physical help with grooming My child requires me to provide considerable physical help with grooming. My child is completely dependent and requires me to do all of his/her grooming			X
DOES YOUR CHILD BATHE HIMSELF/HERSELF FROM THE NECK DOWN (EXCEPT FOR HIS/HER BACK) IN A BATH, SHOWER, OR SPONGE/BED BATH?		My child bathes himself/herself and does not require me to provide any help My child requires me to provide supervision with or without a small amount of physical help with bathing My child requires me to provide considerable physical help with bathing My child is completely dependent and requires me to bathe him/her			X
DOES YOUR CHILD DRESS HIMSELF/HERSELF FROM THE WAIST UP?		My child dresses himself/herself from the waist up and does not require me to provide any help My child requires me to provide supervision with or without a small amount of physical help with dressing from the waist up My child requires me to provide considerable physical help with dressing from the waist up My child is completely dependent and requires me to dress him/her			X
DOES YOUR CHILD DRESS HIMSELF/HERSELF FROM THE WAIST DOWN?		My child dresses himself/herself from the waist down and does not require me to provide any help My child requires me to provide supervision with or without a small amount of physical help with dressing from the waist down My child requires me to provide considerable physical help with dressing from the waist down My child is completely dependent and requires me to dress him/her			X
MOBILITY DOES YOUR CHILD SIT DOWN AND		My child does sit down and get up from a	X		X

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GET UP FROM A CHAIR OR WHEELCHAIR?		<p>chair or wheelchair himself/herself and does not require me to provide any help</p> <p>My child requires me to provide supervision with or without a small amount of physical help to sit down and get up from a chair or wheelchair</p> <p>My child requires me to provide considerable physical help to sit down and get up from a chair or wheelchair</p> <p>My child cannot sit in a chair OR is completely dependent and requires me to place him/her in a chair or wheelchair and lift him/her out of it</p>			
DOES YOUR CHILD GET INTO OR OUT OF A BATH OR SHOWER (WHICHEVER IS USED MORE OFTEN)?		<p>My child does get into or out of a bath or shower and does not require me to provide any help</p> <p>My child requires me to provide supervision with or without a small amount of physical help to get into or out of a bath or shower</p> <p>My child requires me to provide considerable physical help to get into or out of a bath or shower</p> <p>My child is completely dependent and requires me to help him/her get into or out of a bath or shower</p>			X
DOES YOUR CHILD MOVE AROUND BY HIMSELF/HERSELF INDOORS ON A LEVEL SURFACE?		<p>My child moves around indoors on a level surface by himself/herself and does not require me to provide any help</p> <p>My child requires me to provide supervision with or without a small amount of physical help when moving around indoors on a level surface</p> <p>My child requires me to provide considerable physical help when moving around indoors on a level surface</p> <p>My child cannot move around indoors by himself/herself</p>			X
DOES YOUR CHILD MOVE AROUND BY HIMSELF/HERSELF OUTDOORS ON UNEVEN SURFACES?		<p>My child moves around outdoors on uneven surfaces by himself/herself and does not require me to provide any help</p> <p>My child requires me to provide supervision with or without a small amount of physical help to move around outdoors on uneven surfaces</p> <p>My child requires me to provide considerable physical help to move around outdoors on uneven surfaces</p> <p>My child cannot move around outdoors</p>			X
DOES YOUR CHILD GO UP AND DOWN STAIRS?		<p>My child does go up and down 12 steps indoors himself/herself and does not require me to provide any help</p> <p>My child requires me to provide supervision with or without a small amount of physical help to go up and down 12 steps indoors</p> <p>My child requires me to provide considerable physical help to go up and down 12 steps indoors</p> <p>My child cannot go up or down stairs</p>			X
TOILETING DOES YOUR CHILD WIPE		<p>My child uses the toilet and adjusts his/her</p>			X

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HIMSELF/HERSELF AND ADJUST HIS/HER CLOTHING BEFORE AND AFTER USING THE TOILET?		<p>clothing before and after using the toilet. I do not need to provide any help</p> <p>My child requires me to provide supervision with or without a small amount of physical help when he/she uses the toilet</p> <p>My child requires me to provide considerable physical help when using the toilet. This includes adjusting clothing before and after using the toilet</p> <p>My child is completely dependent and requires me to wipe him/her and adjust clothing before and after using the toilet</p>			
DOES YOUR CHILD HAVE BLADDER ACCIDENTS?		<p>My child never has bladder accidents and is able to control his/her bladder functions without help from me</p> <p>My child has occasional bladder accidents but only during either the day or the night, but not both</p> <p>My child has occasional bladder accidents during the day and during the night</p> <p>My child has frequent bladder accidents during the day and/or during the night</p> <p>My child is completely incontinent and requires me to assist him/her with his/her bladder functions (e.g. requires a catheter)</p>			X
DOES YOUR CHILD HAVE BOWEL ACCIDENTS?		<p>My child never has bowel accidents and is able to control his/her bowel functions without help from me</p> <p>My child has occasional bowel accidents but only during either the day or the night, but not both</p> <p>My child has occasional bowel accidents during the day and during the night</p> <p>My child has frequent bowel accidents during the day and/or during the night</p> <p>My child is completely incontinent and requires me to assist him/her with his/her bowel functions (e.g. an enema is required).</p>			X
DOES YOUR CHILD SIT DOWN AND GET UP FROM THE TOILET?		<p>My child does sit down and get up from a toilet by himself/herself and does not require help from me</p> <p>My child requires me to provide supervision with or without a small amount of physical help to sit down and get up from a toilet</p> <p>My child requires me to provide considerable physical help to sit down and get up from a toilet</p> <p>My child cannot sit on a toilet OR requires me to place him/her on the toilet and lift him/her off it</p>			X
Disability					
		Developmental delay	X	X	X
		Intellectual			
		Down's Syndrome			
		Specific Learning			
		Attention Deficit Disorder			
		Autism			

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		Asperger's syndrome			
		Physical			
		Acquired brain injury			
		Deaf blind (dual sensory)			
		VisionHearing			
		Speech			
		Psychiatric			
		Neurological			
		Other			
		Not stated/inadequately described			
Comments		Text	X	X	X
Are there other disabilities?		Yes - No	X	X	X
And, if so, what are they?		(see above list)	X	X	X
Is the effect of the applicant's disability or medical/health care needs on their capacity to manage activities of daily living:		Stable		X	X
		Episodic			
		Improving over time			
		Becoming worse over time			
Carer/Family					
DOES THE PERSON NEED A CARER		The person cannot be left on their own at any time (whether by day or night)	X		X
		The person can only be left on their own for some, but not all, of the time (whether by day or night)			
		No Carer required			
		Paid carer			
DOES THE PERSON HAVE A CARER?		Has a Carer	X		X
		No carer			
		Not applicable - paid carer			
Carer Details					
Primary carer (PC) -first name	X	Text	X	X	X
PC -family name	X	Text	X	X	X
PC residency	X	Co-resident Carer	X	X	X
		Non-Resident carer			
Relationship of primary carer to person	X	Wife/female partner	X	X	X
		Husband/male partner			
		Mother			
		Father			
		Daughter			
		Son			
		Daughter-in-law			
		Son-in-law			
		Other relative – female			
		Other relative – male			
		Friend/neighbour – female			
		Friend/neighbour – male			
		Aunt			
		Uncle			
		Other			
		Wife/female partner			
		Husband/male partner			
		Mother			
		Father			
		Daughter			
		Son			
		Daughter-in-law			
		Son-in-law			
		Other relative – female			

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		Other relative – male			
		Friend/neighbour – female			
		Friend/neighbour – male			
		Aunt			
		Uncle			
		Other			
CURRENT THREATS TO PC - PERSON ARRANGEMENTS?		Carer – emotional stress & strain	X		X
		acute physical exhaustion/illness			
		Carer – slow physical health deterioration			
		Carer – factors unrelated to care situation			
		person – increasing needs			
		person – other factors			
ARE PC- PERSON ARRANGEMENTS SUSTAINABLE WITHOUT ADDITIONAL SERVICES OR SUPPORT?		No, arrangements have already broken down	X		X
		No, carer arrangements likely to break down within months			
		Yes, carer arrangements are sustainable without additional support			
		Not sure			
Comments		Text	X		X
Family					
Who else lives in the family/household?		Text			X
Household/family structure?		Text			X
Relationship		Mother		X	X
		Father			
		Guardian			
		Foster mother			
		Foster father			
		Stepmother			
		Stepfather			
		Brother			
		Sister			
		Grandmother, (paternal)			
		Grandfather, (paternal)			
		Grandmother, (maternal)			
		Grandfather, (maternal)			
		Aunt			
		Uncle			
		Cousin			
		Friend			
		Other			
Name/s		Text		X	X
Age/s		number			X
Household/family structure diagram		Text /diagram (if possible)			X
Impact of the person upon the functioning of the family?		Text			X
Assessor judgement - potential of family to benefit from early intervention		Yes			X
		No			
		Not sure			
Comments		Text			X
Carer/Family (expanded)					
Does the Carer care for more than one person?		Yes			
		No			
Are there other people who provide care? (e.g. network of		Yes	X		X
		No			

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carers, shared caring arrangements)		Not sure			
Type of assistance		Text	X		X
Who from (e.g. family, friends)		Text	X		X
How often (hrs/week)		number	X		X
Comments		Text	X		X
Network of care		diagram (if possible)	X		X
Carer Support					
DOES PC HAVE SOMEONE TO HELP HIM OR HER?		Yes	X		X
		No			
		Not sure			
Comments		Text	X		X
Does PC receive a Pension or Benefit?	X	Aged pension	X		X
		Veterans' affairs pension			
		Disability support pension			
		Carer payment (pension)			
		Unemployment related benefits			
		Other government pension or benefit			
		No government pension or benefit			
		Carer allowance			
		Not stated/inadequately described			
		Not sure			
Has PC been given information about available support services?		YesNoNot sure	X		X
Does PC need practical training in lifting, managing medicine or other tasks?	X	Yes	X		X
		No			
		Not sure			
What are the most positive aspects about caring for the family member?		Text			X
Comments		Text	X		X
Health Conditions					
Include all relevant issues e.g., allergies, acute medical conditions, disabilities, continence, dental developmental, mental health, As reported by person or carer		Text	X		X
Confirmed by health professional		Yes	X		X
		No			
Current treatments/therapies		Text	X		X
Comments		Text	X		X
Aids and Equipment					
Is person currently using any aids and equipment?		Home modifications	X	X	X
		Car Modifications			
		Self-care Aids			
		Communication Aids			
		Medical Care Aids			
		Aids for Reading			
		Hearing Aid			
		Support and Mobility Aids			
		Other (list):			
Comments		Text	X		
Assessor, do you think that home modifications may be required?		Yes	X		
		No			

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Assessor, do you think that the provision of aids and / or equipment may be required?		Yes No	X		
Does the consumer have the capacity to become more independent if provided with appropriate services or resources?		Yes No	X		
Comments		Text	X		
Dementia					
IS THERE EVIDENCE OF MEMORY LOSS OR DEMENTIA?		Yes No	X		
Is there a medical diagnosis of dementia?		Yes No	X		
If Yes, has there been a recent cognitive assessment?		Yes No	X		
Comments		Text	X		
Pain					
HOW MUCH BODILY PAIN HAVE YOU HAD DURING THE PAST 4 WEEKS?		None Very Mild Moderate Severe Very Severe	X		
If bodily pain, has consumer seen a health professional about this problem?		Yes No	X		
If not, is a referral warranted?		Yes No	X		
Comments		Text	X		
Falls					
HAVE YOU HAD A FALL IN THE PAST 6 MONTHS?		Yes No Not sure	X		
If Yes, record number of falls ...		Number	X		
... and what was the outcome?		Text	X		
Vision					
Do you use glasses?		Yes No	X		
Is your eyesight for reading without glasses?		Excellent Good Fair Poor	X		
Is your eyesight for reading with glasses?		Excellent Good Fair Poor	X		
Is your long distance eyesight without glasses?		Excellent Good Fair Poor	X		
Is your long distance eyesight with glasses?		Excellent Good Fair Poor	X		
Comments		Text	X		
Hearing					
Do you use a hearing aid?		Yes No	X		
Is your hearing without hearing		Excellent	X		

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aid		Good Fair Poor			
Is your hearing with hearing aid		ExcellentGoodFairPoor	X		
Comments		Text	X		
Speech / Swallowing					
DO YOU HAVE PROBLEMS WITH SPEECH AND/OR SWALLOWING?		Yes No	X		
If yes, have you seen a health professional about this		Yes No	X		
Comments		Text	X		
Medication					
Are you receiving medication?		Yes No	X		
Do you use a Webster pack or similar?		Yes No	X		
DOES THIS PERSON GENERALLY LOOK AFTER AND TAKE HER OR HIS OWN PRESCRIBED MEDICATION WITHOUT REMINDING?		Reliable with medication Slightly unreliable Moderately unreliable Extremely unreliable	X		
What is the schedule for medication?		Text	X		
Comments		Text	X		
Expanded Health Conditions					
Oral health					
PROBLEMS WITH TEETH, GUMS, DENTURES, INCLUDING ELIGIBILITY TO ACCESS SERVICES?		Yes No	X		
Comments		Text	X		
Feet					
PROBLEMS ONE OR BOTH FEET?		Yes No	X		
Comments		Text	X		
Vaccinations					
Influenza Status		Text	X		
Influenza Date		Date	X		
Influenza By who		Text	X		
Pneumococcus Status		Text	X		
Pneumococcus Date		Date	X		
Pneumococcus By Who		Text	X		
Tetanus Status		Text	X		
Tetanus Date		Date	X		
Tetanus By Who		Text	X		
Other 1		Text	X		
Other 1 Status		Text	X		
Other 1 Date		Date	X		
Other 1 By Who		Text	X		
Other 2		Text	X		
Other 2 Status		Text	X		
Other 2 Date		Date	X		
Other 2 By Who		Text	X		
Driving					
Drives a motor vehicle?		Yes No	X		
Fit to drive		Yes No	X		

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Comments		Text	X		
Continence					
How frequently is urine leakage experienced?		Never Sometimes Often	X		
What amount of urine is lost each time?		A few drops A Little More	X		
SEVERITY INDEX (FREQUENCY X AMOUNT)		Number	X		
Is this related to coughing or sneezing?		Yes No	X		
How frequently is faecal incontinence experienced (leak, have accidents or lose control with stool)?		Never Sometimes Often	X		
Comments		Text	X		
Height and Weight					
Weight (Kg)		Number	X		
Height (metre)		Number	X		
BMI		Number	X		
Blood Pressure/Pulse					
Systolic BP		Number	X		
Diastolic BP		Number	X		
Pulse		Regular Irregular	X		
Pulse rate			X		
Consider check for postural hypotension?		Yes No	X		
Health Behaviours					
Regular health checks					
Regular health checks		Yes No	X		
If yes, record last date or year		Date	X		
If yes, record health screens in last 2 years (e.g. pap smear, breast, prostate)		Text	X		
Smoking Status		never smoked has quit smoking (record when) currently smokes	X		
Alcohol					
How often do you have a drink containing alcohol?		Never Monthly Once a week 2-4 times per week 5+ per week	X		
Number of standard drinks on a typical day when drinking?		Number			
How often do you have more than 6 standard drinks on one occasion?		Never Monthly Once a week 2-4 times per week 5+ per week	X		
Nutrition					
HAVE YOU LOST WEIGHT RECENTLY WITHOUT TRYING?		Yes No Not sure	X		

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If yes, how much weight have you lost? (in kilograms)		1-5 6-10 11-15 >15	X		
Comments		Text	X		
Have you been eating poorly because of decreased appetite?		Yes No Not sure	X		
HYDRATION					
Do you regularly drink at least 8 cups of fluid every day?		Yes No Not sure	X		
If no Have you recently decreased your fluid intake?		Yes No	X		
PHYSICAL ACTIVITY					
Would you do at least 30 minutes of moderate physical activity (such as walking or yard work or any other type of exercise) on most days of the week?		Yes No	X		
During the past 4 weeks, what was the hardest physical activity you could do for at least 2 minutes?		Very heavy (for example) run, fast pace; carry a heavy load upstairs or uphill (25 lbs, 10 kg) Heavy (e.g. jog, slow pace; climb stairs or a hill at moderate pace) Moderate (e.g. walk, medium pace; carry a heavy load level ground (25lbs, 10kg)) Light (e.g. walk, medium pace; carry a light load on level ground (10 lbs, 5 kg)) Very light (e.g. walk, slow pace; wash dishes)	X		
Comments		Text	X		
3 - Social and Emotional profile					
DURING THE PAST 4 WEEKS, WAS SOMEONE AVAILABLE TO HELP THE PERSON IF THEY NEEDED AND WANTED HELP? FOR EXAMPLE IF THE PERSON		as much as I wanted quite a bit some a little not at all	X		X
-FELT VERY NERVOUS, LONELY OR BLUE					
-GOT SICK AND HAD TO STAY IN BED					
-NEEDED SOMEONE TO TALK TO ASSESSOR, IF NOT AT ALL OR A LITTLE ASK "DOES THE PERSON USUALLY HAVE ENOUGH SUPPORT		Yes No	X		
Comments			X		X
What sorts of social activities is the person involved in outside the home?		Text			X
Does the person have a range of friends outside of home?		Yes No			X
What are his/her usual leisure activities, and hobbies?		Text			X
Are they involved in		Education			X

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and for how long usually per week?		Employment Other activities- please specify number			X
Comments				X	X
Would the person be interested in finding out about... Assessor, provide relevant examples, e.g. information about relevant services including social support for the family	X	Yes No Not sure	X		X
Comments:		Text	X		X
KESSLER PSYCHOLOGICAL DISTRESS SCALE (K10)					
In the past 4 weeks about how often did you feel... Tired out for no good reason? Nervous? So nervous that nothing could calm you down? Hopeless? Restless or fidgety? So restless you could not sit still? Depressed? That everything was an effort? So sad that nothing could cheer you up? Worthless?		Score 1-None of the time 2-A little of the time 3-Some of the time 4-Most of the time 5-All of the time	X		
Total K-10 Score:		Number	X		
Counselling					
Have you talked to a health professional or a counsellor about how you are feeling?		Yes No Not sure			
Comments:		Text	X		X
Expanded Social and Emotional					
Sleeping					
HAVE YOU HAD ANY DIFFICULTY SLEEPING?		Yes No	X		
Comments		Text	X		
FAMILY AND PERSONAL RELATIONSHIPS					
Does this person generally make and/or keep up friendships?		Friendships made or kept up well Friendships made or kept up with slight difficulty; Friendships made or kept up with considerable difficulty No friendships made or none kept up	X		
Does this person generally have problems (e.g. friction, avoidance) interacting / living with others?		No obvious problem Slight problems; Moderate problems; Extreme problems	X		
Comments		Text	X		
Financial/Legal					
WHAT IS THE EMPLOYMENT STATUS OF PERSON?	X	Employed/self employed Sheltered Child/Student Home duties	X		X

Data Item	ISR	Code/Text/Data type	ONI- N	PSP	ONI- IAM
		Unemployed			
		Retired for age			
		Retired for disability			
		CDEP			
		Other			
Does the person have any financial or legal issues that may effect services	X	Yes	X		X
		No			
		Not sure			
Comments	X	Text	X		X
WHO ASSISTS WITH FINANCIAL DECISIONS OF THE PERSON?	X	No-one	X		X
		Significant Informal Assistance			
		Power of Attorney			
		Parent or Guardian			
		Formal Financial Administrator or Manager			
Is the person capable of making their own decisions?	X	Yes	X		X
		No			
		Not sure			
Who assists person in making decisions?	X	No-one	X		X
		Significant Informal Assistance			
		Power of Attorney			
		Advance Health Directive			
		Person responsible or appointed guardian			
Comments	X	Text	X		X
Does the Mental Health Act affect person?	X	YesNoNot sure	X		X
Comments	X	Text	X		X
Are there any other relevant legal issues		Yes			
		No			
		Not sure			
Comments	X	Text	X		X
The Future					
DOES THE PERSON OR PARENT/CARER HAVE ANY CONCERNS FOR THE PERSON'S FUTURE?		Yes			X
		No			
		Not sure			
Comments:		Text		X	X
ARE THEY OR PARENT/CARER ABLE TO IDENTIFY ANY GOALS FOR THE PERSON THAT THEY WOULD LIKE TO ACHIEVE IN THE NEAR FUTURE?		Yes			X
		No			
		Not sure			
Comments:				X	X
What kind of support would make the biggest difference for the future?		Text		X	X
Type of assistance (what)?		Text		X	X
For whom – carer or person?		Text			X
Who from (e.g. agency, family, friends)?		Text			X
How often (hrs/wk)?		Number			X
Comments:		Text		X	X
Assessor: Prompt for assistance in practical training needs in lifting, managing medicine or other tasks and in maintaining own health.	X	Text			X

Appendix 3: Illustrations of models relevant to outcome measurement from a range of CHSD projects

This Appendix shows examples from the body of research and development projects in community care that illustrate how a priority rating and classification approach can work in practical terms.

While functional capacity is of critical importance in driving the need for community care services, it is not the only measure of need or the only client-related cost driver. Other important client-related cost drivers (or variables) also need to be captured to gain a comprehensive picture of the population for different programs. The issues to be resolved in outcome measurement are around getting agreement on the range of variables that are potential candidates for inclusion in any proposed classification.

In the sub-acute and non-acute parts of the health sector these are:

- Primary diagnosis (ICD, Clinical Stream, DRGs or other groupings)
- Level of functional need
- Level of service provided (ideally related to level of client need)
- Occasions of service received (by service outlet or care setting)
- Professional service type received (nursing, allied, medical)
- Case type (characteristics of the client and the goal of intervention)
- Care package received (bundled services over a period of time).

A number of different approaches to community care and support classification issues already exist. For example, the AN-SNAP community classification uses five generic variables:

- Case Type (palliative; rehabilitation; geriatric evaluation and management; psychogeriatric; or maintenance or support)
- Assessment only or intervention episode
- Age
- Provider type (sole practitioner or multidisciplinary)
- Self-care function.

AN-SNAP also incorporates variables that are specific to particular Case Types. These are:

- Phase (palliative; psychogeriatric)
- Impairment (rehabilitation)
- Severity (palliative; psychogeriatric).

There are many good examples of working systems based on these or similar dimensions (Eagar et al. 2004). However, not all dimensions create equally desirable incentives. For example, for reasons of promoting continuity across programs, there are likely to be concerns about the incentives that are created by the use of a model that is determined solely on the professional service type received, for example in systems based on nursing.

There are also variables that have been identified in previous studies as leading contenders in any future developments. Some of these are:

- Carer availability
- Social isolation
- Domestic functioning (instrumental ADLs)
- Socio-economic and language status
- Risk behaviour status.

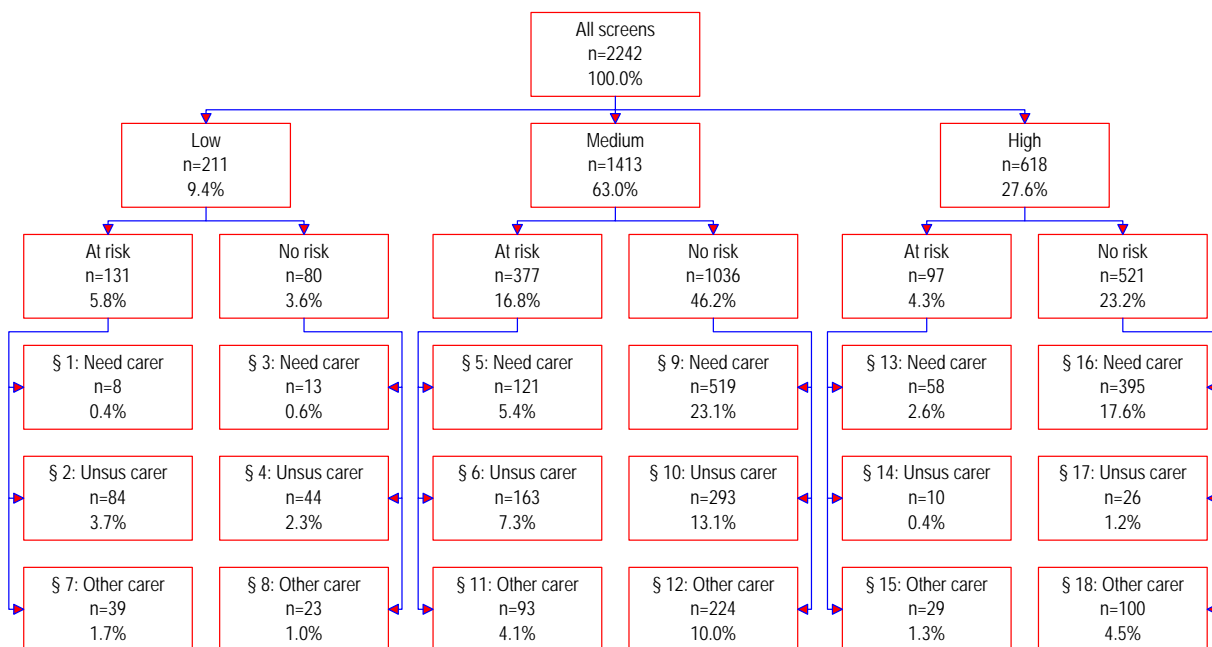
The Home Care priority rating model using function, risk and carer status as a decision tree for assigning priority

The Functional Screening tool is set up within the ADHC Client Information System(CIS) and used routinely for each referral to HCS. This is firmly embedded into RAC/HCS process since CIS was implemented for RAC in Nov 2006.

Branch capacity and FST Category range is updated in CIS by the branch managers and referrals are progressed for assessment based on the parameters set by the branch, CIS then compares the outcome of the FST assessment i.e. category, and current hours capacity at the specific time of referral. These details are recorded in CIS for each referral for future reference if needed.

There is a clear opportunity to initiate a similar model to what is used by RAC, to other parts of ADHC and the wider community care sector.

Figure 2 Home Care priority rating model



Key:

Function: Low function (total screen score < 6 or self care score < 2)

Medium function (self care item < 2 or domestic item = 0)

High function (Not low or medium function)

Risk: No cognitive or behavioural risk ('no risk') (Items 8 & 9 > 0)

At risk due to either cognition or behaviour ('at risk') (Either items 8 or 9 = 0)

Carer: Needs a carer ('need') (Item 10 = 2)

Current carer arrangements are unsustainable ('unsus') (Item 10 = 1 and Item 11 < 3)

Either no carer required or sustainable carer arrangements ('other') (Item 10 = 3 OR Item 10 = 1 and Item 11 > 2)

§: The service priority rating assigned to each group of consumers. §1 is the highest priority group. §18 is the lowest priority group.

Post School Programs classification approach

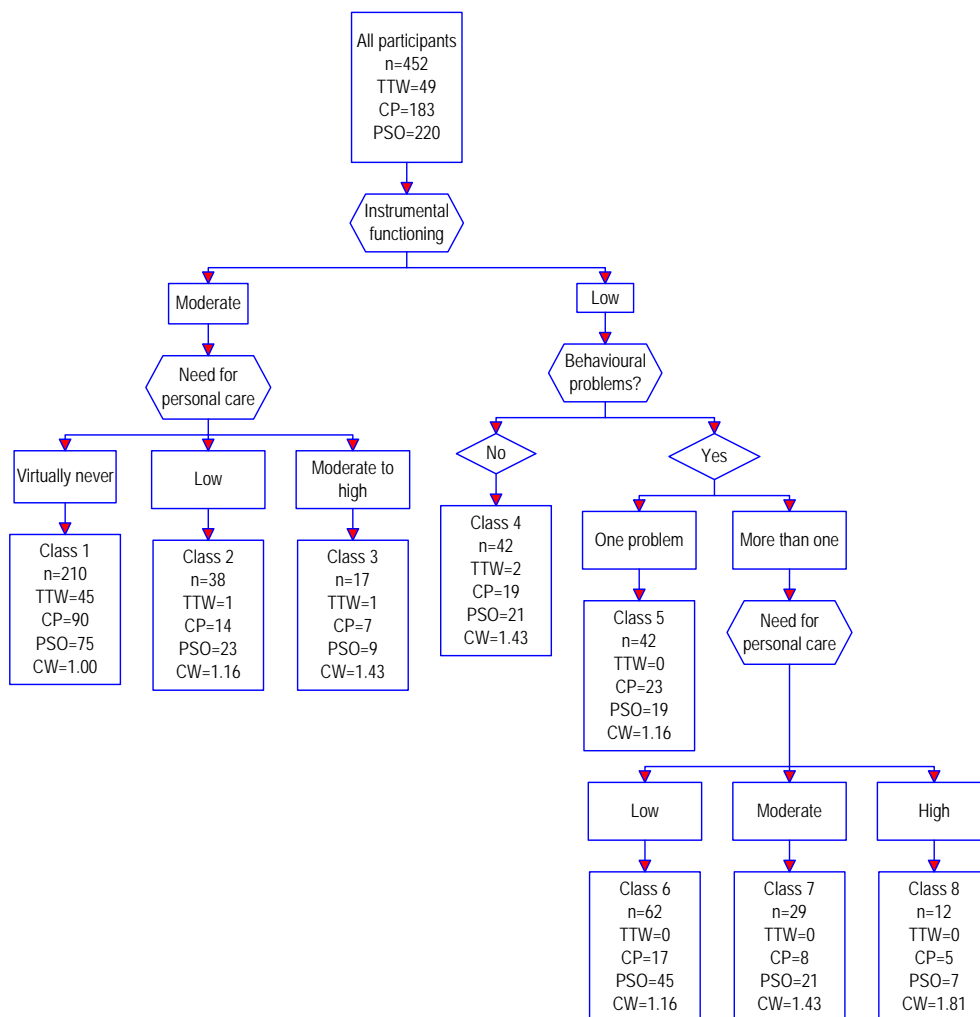
The data analysis in previous reports on the PSP demonstrated considerable variation in need between consumers in the programs, while there was comparatively little variation in the amount of funding allocated to individual consumers. Introducing the idea of classification and costing was a way to systematically address this inequity between need and funding. There is a relationship between classification, costing and funding in all areas of human services.

In essence, if clients can be appropriately classified, their costs can then be interpreted in a meaningful way, which in turn allows informed decisions to be made about funding. The same key principles of classification can apply in the community sector in general. The objectives are:

- To identify those consumer attributes that drive costs;
- To measure the relationship between need and cost (by a costing study); and
- To develop a set of resource homogeneous classes that can form the basis of a Generation 1 Consumer Classification for the Program.

The costing study captured a snapshot of Post School Program services and clients in 2005. The outcome was a client classification containing eight classes.

Figure 3 Profile of the PSP classification by program



Recommended consumer classes from the Illawarra Coordinated Care Trial

The 22 primary consumer classes designed to be used in the trial were:

1. Palliative care, stable
2. Palliative care, unstable or deteriorating
3. Palliative care, terminal
4. Rehabilitation/functional gain, amputation
5. Rehabilitation/functional gain, brain dysfunction
6. Rehabilitation/functional gain, fractured NOF
7. Rehabilitation/functional gain, stroke
8. Rehabilitation/functional gain, all other
9. Geriatric Evaluation and Management, high need, without carer
10. Geriatric Evaluation and Management, high need, with carer
11. Geriatric Evaluation and Management, medium need, without carer
12. Geriatric Evaluation and Management, medium need, with carer
13. Geriatric Evaluation and Management, low need, old (85 plus)
14. Geriatric Evaluation and Management, low need, young (<=84 years)
15. Maintenance and support, high need, without carer
16. Maintenance and support, high need, with carer
17. Maintenance and support, medium need, without carer
18. Maintenance and support, medium need, with carer
19. Maintenance and support, low need, old (85 plus)
20. Maintenance and support, low need, young (<=84 years)
21. Prevention and Early Intervention, old (85 plus)
22. Prevention and Early Intervention, young (<=84 years)

In addition to these 22 consumer classes, there were 8 community consumer classes designed for diagnosis related acute and post-acute care. These classes were supplementary classes in the sense that a consumer who requires acute or post-acute care would be allocated on a short-term basis to one of these classes *in addition to* their existing class.

To assist continuity the consumer would receive their existing package of community services supplemented by interventions designed to address their diagnosis-related acute care needs. When the acute problem is resolved, the supplementary package would cease.

The 8 supplementary package classes were designed to cover specific programs of a time-limited nature to address specific health conditions or post-hospital support packages:

23. Diagnosis related acute and post-acute care, vascular
24. Diagnosis related acute and post-acute care, neurological/dementia
25. Diagnosis related acute and post-acute care, cardiac
26. Diagnosis related acute and post-acute care, COPD
27. Diagnosis related acute and post-acute care, infections requiring IV antibiotics
28. Diagnosis related acute and post-acute care, all other medical conditions
29. Diagnosis related acute and post-acute care, wound management without complications
30. Diagnosis related acute and post-acute care, wound management with complications

Determining Classes – for example Palliative Care Phase

The palliative care phase is the stage of the patient's illness. Palliative care phases are not sequential and a patient may move back and forth between phases. The health care professional reviews the patient/client and records phase changes if and when they occur during each episode. Palliative care phases provide a clinical indication of the level of care required and have been shown to correlate strongly with survival within longitudinal, prospective studies.

Phases are defined in terms of the following criteria as these highlight the essential issues to be considered when assigning a client to a phase.

<p>Phase 1: Stable</p> <p>All clients not classified as unstable, deteriorating, or terminal.</p> <ul style="list-style-type: none">▪ The person's symptoms are adequately controlled by established management. Further interventions to maintain symptom control and quality of life have been planned.▪ The situation of the family/carers is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.
<p>Phase 2: Unstable</p> <ul style="list-style-type: none">▪ The person experiences the development of a new unexpected problem or a rapid increase in the severity of existing problems, either of which require an urgent change in management or emergency treatment▪ The family/carers experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team.
<p>Phase 3: Deteriorating</p> <ul style="list-style-type: none">▪ The person experiences a gradual worsening of existing symptoms or the development of new but expected problems. These require the application of specific plans of care and regular review but not urgent or emergency treatment.▪ The family/carers experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.
<p>Terminal</p> <p>Death is likely in a matter of days and no acute intervention is planned or required. The typical features of a person in this phase may include the following:</p> <ul style="list-style-type: none">▪ Profoundly weak▪ Essentially bed bound▪ Drowsy for extended periods▪ Disoriented for time and has a severely limited attention span▪ Increasingly disinterested in food and drink▪ Finding it difficult to swallow medication <p>This requires the use of frequent, usually daily, interventions aimed at physical, emotional and spiritual issues.</p> <ul style="list-style-type: none">▪ The family/carers recognise that death is imminent and care is focussed on emotional and spiritual issues as a prelude to bereavement.
<p>Bereaved phase</p> <p>Death of the patient has occurred and the carers are grieving. A planned bereavement support program is available including referral for counselling as necessary. Record only one bereavement phase per patient - not one for each carer/family member.</p>

Case management levels attached consumer classes - for example in the Illawarra Coordinated Care Trial

The planning for the second round of the Illawarra Coordinated Care Trial (ICCT) used the experience from the evaluation of the first round to clarify four levels of case management in a model that can help to support a continuum of needs. The first two levels are progressively more intensive in terms of case management resources where the aim is improving continuity/integration of services for the mix of complex and higher dependency clients.

Level 3 is for 'navigation support' for short term interventions and is where clients with rehabilitation potential, i.e. where 'enablement' or 'wellness' interventions are suitable instead of, or along with, traditional community care services.

Case management level 4 is different from the others. Levels 1 to 3 are graded in terms of intensity of effort. This is not the case with level 4, which would be provided for all consumers who will benefit from it at discharge from hospital or when community care is being put into place as an alternative to hospitalisation. It will occur concurrently with one of the other levels. In this level, a consumer would be co-case managed during the period in which they are acutely unwell. This is to provide a structured opportunity to prevent hospitalisations or, if that is not possible, to achieve successful reductions in length of hospital stay.

The specific tasks required for the four levels of case management are:

Case Management Level 1

- assertive management of complex problems within context of multidisciplinary team
- assessment
- coordination of range of services/programs
- commissioning services/programs
- seamless transfer to another case manager if appropriate
- time commitment: 26 hours a quarter

Case Management Level 2

- assertive management and commissioning of services/programs
- commissioning services/programs make referral for assessment when appropriate
- seamless transfer to another case manager if appropriate
- time commitment: 8 hours a quarter

Case Management Level 3

- purchase of one-off early identification/preventive/information services
- 3 monthly telephone contact with consumer using screening tool
- make referral for assessment when appropriate
- seamless transfer to another case manager if appropriate
- time commitment: 1 hour a quarter

Case Management Level 4

- discharge planning
- "hospital in home" coordination
- commissioning services/programs skills
- co-case management of consumer when they are classified as community Diagnosis Related Acute and Post Acute
- time commitment: 8 hours per discharge/prevented admission

Standard set of intervention codes for care packages under the proposed ICCT

<i>Typical interventions provided as part of planned package</i>	<i>Unit of costing</i>	<i>Unit cost</i>
A1 'ACAT Plus'	per hour	\$45
A2 Accredited CCT assessment	per assessment	\$120
A3 Allied health therapy	per session	\$45
A4 Assessment - allied health, 1 discipline	per assessment	\$45
A5 Assessment - allied health, 2 or more disciplines	per assessment	\$90
A6 Assessment - medical only	per assessment	\$70
A7 Assessment - multidisciplinary	per assessment	\$120
A8 Assessment - nursing only	per assessment	\$45
B1 Bereavement counselling	for 3 months	\$180
B2 Bereavement support for	3 months	\$60
C1 Case management/coordination – Level 1	for 3 months	\$1,040
C2 Case management/coordination – Level 2	for 3 months	\$320
C3 Case management/coordination – Level 3	for 3 months	\$40
C4 Case management/coordination – Level 4	for 3 months	\$480
D1 Centre-based day care	per day	\$25
D2 Diagnostic imaging	per test	\$100
G1 Group contact	per group	\$20
H1 Home help	per hour	\$25
H2 Home maintenance	per hour	\$25
M1 Meals	per day	\$5
M2 Medical treatment	per consult	\$30
M3 Medication dispensing, administration or supervision	per visit	\$10
M4 Medication prescription	per consult	\$5
M5 Monitoring via home visit	per visit	\$25
M6 Monitoring via other means	for 3 months	\$50
N1 Nursing - general interventions	per visit	\$45
N2 Nursing - technical intervention not elsewhere specified	per visit	\$45
O1 Other food services	per day	\$5
P1 Pathology testing	per test	\$60
P2 Patient education	per session	\$30
P3 Personal care including assistance with ADLs	per visit	\$35
P4 Provision of linen	per day	\$10
R1 Respite care	per hour	\$25
S1 Social support	per hour	\$25
S2 Counselling and support	per hour	\$45
T1 Transport	per trip	\$10
W1 Wound management	per visit	\$25

These were indicative costs only and the total cost of an expected community care package is the sum of the selected components

Examples of other interventions (not part of detailed care package costing) were identified as:
 Specialist or GP Assessments, Cardiac, Diabetes or COPD program
 One-off items that may be provided during trial
 Care planning/case conference
 Home modification
 Provision of aids or appliances
 Carer supplement - 1 week (pall care & rehab only)
 High cost dressings
 Self-management program

Appendix 4: Examples of Best Practice

International examples

Community care is a sector where the techniques of health care outcome measurement is mostly less relevant and referrals to health teams are the most appropriate responses, however some familiarity with how outcomes-based models work in other sectors can be useful at the conceptual by way of clarifying how particular tools can work. An example of the tool development work associated with specific health conditions is the Patient-assessed Health Instruments Group (PHIG) which is part of the National Centre for Health Outcomes Development and is based in the Unit of Health-care Epidemiology at the University of Oxford. The PHIG is a multidisciplinary team with a range of experience in the measurement of health-related quality of life, and the instruments developed by group members for use within specific populations include the Oxford Hip Score, Parkinson's Disease Questionnaire and the UK Seattle Angina Questionnaire. This group has also contributed to the evaluation of widely-used generic instruments including the EuroQol and SF-36, and individualised instruments, including the Patient Generated Index (<http://phi.uhce.ox.ac.uk/>).

In community care the case still needs to be made more clearly about how the concepts of outcome measurement work and why they are relevant to improving the quality of services. A useful summary in Table 4 below compares outcomes focussed approaches with service led output approaches. The table summarises some of the constraints that have been identified in the community care system, in particular in Scotland, but with relevance to Australia. It also identifies the potential for explaining these concepts in a way that can assist agencies and providers in overcoming these barriers.

Table 3 *Service led output and outcomes focussed approaches*

Service Led Output Focused	Outcomes focused
Current tools encourage information gathering through standardised question and answer approaches to assessment, support planning and review	Decision making informed by semi-structured conversations with individuals in assessment, support planning and review
Tick box approach to assessment	Analytical skills involved in assessment
The person's views may be included in decision-making	The person's views/preferences are central to decision-making
The person is viewed as a client, service user or patient	The person is a citizen with rights and responsibilities
Where needs link to strict eligibility criteria, the assessor is required to maximise individual difficulties to access services	Involves consideration of difficulties, limitations and aspirations or goals. The priority is to identify what to work towards
If the person is deemed eligible, identified needs are matched to a limited range of block provided services, resulting in service driven approaches	Identifying outcomes involve considering a range of solutions/strategies including the role of the person, family supports and community based resources
Where needs are tied to eligibility criteria, preventive work with people with low level needs may be excluded	Outcomes allow preventive work to take place while services and resources are prioritised for those most in need
Focusing exclusively on deficits and difficulties, and how needs are to be met, results in a focus on tasks and in services which do things to people	By focusing on strengths, capacities and goals, while mindful of limitations, the role of the person is maximised. Services do things with people
Matching needs/deficits to services tends to result in static service delivery	Outcomes may change in the person's life journey and so should be revisited
Where outcomes are identified, these tend to be professional or organisational outcomes e.g. improved nutrition, or avoid delayed discharge	Outcomes are what matter to the person, though often consistent with professional and organisational outcomes e.g. being able to get out and about.
Starting from what services are currently available restricts communication and limits options	Starting from the person's priorities supports enabling relationships, creates clarity and identifies goals at an early stage. Being listened to, involved and respected results in better outcomes

Source: Miller et al. (2009)

The obvious conclusion from the arguments summarised by the table is that the traditional 'outputs' approach provides few insights into how well organisations are actually helping their clients. This conclusion has been reinforced by a recent review in the Australian context of child and youth services (Australian Research Alliance for Children and Youth [ARACY], 2010).

An example of the limits of the service-led approach is the reporting that takes place under the HACC MDS. Data collection is mandatory for service providers on an ongoing basis as a condition of their funding. The net result is that a lot of 'output' data is collected but not routinely analysed and fed back to providers, and there is already some recognition of the lack of data relating to the effects of services on the people who use them (Simpson-Young and Fine, 2010). Output data is not only easier to collect than data on impacts or outcomes, it is also easier to aggregate (ARACY, 2010). This is particularly relevant in a complex system like the community care sector

Research by the Joint Improvement Team in Scotland has been part of a long term development pathway, and is now called the *Talking Points* approach³, focused on the outcomes important to users of community care services and their unpaid carers. Outcomes in this context were understood both as the *goals* that users and carers wanted to achieve in partnership with health and social care services, and as the *impact* or effect of services on individual lives.

The frameworks used in Scotland have been extensively piloted since 2006 and were adapted from a ten-year programme of research on service user and carer outcomes at the University of York. A team at the University of Glasgow adapted those frameworks into the service system in collaboration with three user research organisations, to ensure that it reflected the priorities of a broad range of community care service users, and used accessible language.

The philosophy behind this approach emphasises the strengths, capacity and resilience of individuals, building on natural support systems and on good practice, and was reported as requiring a significant 'culture shift' because a focus on outcomes supports practice lost by previous assessment and planning processes.

The approach is also reported as capturing valuable data for evaluating, planning and improving services. A practical consideration arising out of this work is that program managers should carefully consider what is required to be reported 'up' and what is more usefully left to be considered at the agency level, referred to as '*below the waterline*' (Bruce, 2010).

This adaptation of the original York/SPRU model builds on the recognition that service users' main concerns are outcomes described in the following way:

- Maintenance outcomes focus on trying to maintain the quality of life of the individual; despite sometimes deteriorating health (examples include feeling safe and social contact).
- Change outcomes result from removing barriers to achieving quality of life, or reducing risks (examples include reduced symptoms such as feeling less depressed and improved confidence), and
- Process outcomes result from the way in which services interact with people (examples include being listened to and feeling respected).

The model has been adapted to include outcomes for carers under the following categories:

- Quality of life of the cared for person
- Quality of life of the carer
- Coping with caring, and
- Process outcomes

³ See Talking Points: Personal Outcomes Approach <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/>

The work in Scotland is progressing on the use of *Talking Points* information for service planning, commissioning, performance management and self assessment. The Joint Improvement Team (JIT) is the body that has carriage of the work program and it has a website that provides access to the body of work produced so far (<http://www.jitscotland.org.uk/>) and this is used to promote a 'community of practice' to assist in the continued adaptation of the tools and resources. <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/>

What carers and care recipients think will work for them

The service provider agencies consulted indicated that there is willingness for agencies in the field to work together towards a common approach. They pointed out that a number of agencies are already sharing their experiences with evidence based outcomes measurement tools and see this as a way to work towards more personalised service responses. The aim of the interview component of the exploratory study was to discuss the feasibility of measuring client/carer outcomes in community care with care providers and their clients. The questions for the agencies designed to promote relevant discussion were:

- What tools do you currently use for assessing client/carer need and risk?
- How does your organisation manage priority for services and capacity to benefit?
- How does your service manage its reporting in the 'case management' space?
- Is it realistic to turn existing data collection mechanisms into 'evaluation friendly' or outcome measurement tools?
- How do you define an 'episode of care', a 'goal of care' and how do you classify your clients?
- Does goal attainment scaling make sense for understanding the goal of care?
- Do you have any comments on the useability of current tools in the area of more consumer-directed care?

Ethical approval to interview agency staff, care recipients and carers was provided by both the University of Wollongong/Illawarra Area Health Service Human Research Advisory Committee and the Uniting Care NSW ACT Research Advisory Group. Participants were asked to complete a consent form once they were made aware of the details of the study provided in the relevant consent sheet.

We conducted agency level interviews with five agencies:

- The Benevolent Society (TBS) has an active research and evaluation unit and produces a regular series of Research into Practice Briefings.
- Uniting Care Ageing (UCA) provides a wide range of community support services and has an innovative 'Wellness Centre' in a re-developed day centre facility where an active rehabilitation model is promoted through exercise classes.
- Community Care Northern Beaches has been funded by ADHC for its preventive 'Enable Me' best practice model targeting the relatively 'well' aged population who are HACC eligible but not engaged with traditional community support services.
- The Disability Trust Illawarra supports a full range of service types for people with disabilities and each year conducts a survey of a sample of its clients to gauge satisfaction.
- Interchange Respite Illawarra has organised a system of assessment and information exchange system for respite⁴.

We also participated by invitation in a workshop with Macquarie University's Centre for Research on Social Inclusion with a case management interest group who have been recognised as agencies developing best practice models.

⁴ See <http://info.s2s.org.au/s2s-plus-service-record-system>

As a way of testing whether findings from the literature made sense for carers and care recipients in the NSW community care context, three questions were presented to people contacted through the agencies that were used to assist in the exploratory study. A small number of clients were consulted and the carers of people with disabilities were recruited through an email request from Carers NSW. The questions were, in considering what you expect from the services you are receiving:

- What would you like changed?
- How could those things be changed?
- How would you know that things had changed for the better?

The purpose of the interviews was to test the evidence found in the literature with people currently in contact with the service system. The interviews were conducted over the telephone and face-to-face. The interviews were recorded by taking notes that were then transcribed and a summary of what was recorded was sent to the agencies for them to check that the interpretations were accurate.

In conducting the verification consultations with agencies and their service users there was an evident interest in approaches based on 'wellness' models and more active 'enablement' and 're-ablement' approaches. This orientation around these more complex goals for community care and support has arisen from increased agency and program level attention to the task of individualising and personalising care for their clients and carers and suggests there is growing interest in local settings as well as internationally in the shift from service-led to client-focussed models.

In exploring what works for care recipients, the interviews highlighted the importance of the special focus on helping people navigate *all* parts of the service continuum, from prevention and early intervention, enablement and wellness to rehabilitation after an acute episode, to maintenance care and support, help with home modifications and changes of housing to better meet needs, through to end of life care.

A small number of interviews were conducted with carers and clients of agencies that agreed to assist the exploratory study. This was not a survey method as the aim was verification of the wider findings rather than a detailed investigation, so the interviews were recorded verbatim and their issues summarised as far as possible in their own words.

The carers' and client's circumstances and major concerns were:

- A woman who cares for her husband who has severe brain damage. She additionally has 2 healthy younger children. This high level of responsibility leads her to be very time poor and stressed.
I would like a break, some time apart from my family. If someone, or a service could take the person I care or away from me for a while. If I could go on a holiday for myself. I would know that things had changed for the better because I would have the time to recover and feel fresh again.
- A woman who cares for a daughter with quadriplegia who needs to be connected to a type of life support machine, she spoke of the expense of the equipment and how difficult it is to maintain.
I need more help to relieve the pressure I feel from needing to care. What I would like is more respite caring. I would like to spend less time caring each day. I would know that things had changed for the better because I would have more time to myself, to do what I want to do.
- A woman who cares for an adult son who has Down's syndrome and autism. His behavioural problems cause great difficulties. She expressed feelings of loneliness and frustration due to a lack of communication with her son.
Loneliness - I do not feel I am getting anything out of caring. There is not much available of interest for me to do. I wish I had other social events other than being around other carers. I would know that things had changed for the better because I would worry much less about my responsibilities and have more free time.
- A woman who cares for an adult son who has quadriplegia.

What I would most like is for him to get better - to change his life and to make things more positive in his life. I would know that things had changed for the better if he improved.

- Cares for an adult son who has Down's syndrome and autism. His behavioural problems cause great difficulties. She expressed feelings of loneliness and frustration due to a lack of communication with her son.

I would like more financial security. I would like better stability and less expenses. I would know that things had changed for the better if I could give my son a better quality of life.

- A husband and wife who both care for an adult daughter who is 23 years old and requires high levels of support.

We would like to see improvements in the way services work together. We would like permanent care for our daughter. We would know that things had changed for the better because we would not be battling the system any more. We would be happy knowing that our daughter is happy.

- Parent (mother) of young adult (early 40s) with disabilities, currently living in a group home. Better medical follow-up and continuity because staffing ratios in group homes make continuity with medical care hard to arrange. What should change is putting more medical and allied health supports in place and re-assessment of need is important. Building in 'quality of life' indicators in group homes is important – physical and psychological – inner and outer – client and carer – safety, risk and stability – and recognition that a whole family can be carers – not just a 'primary' carer. Those things would tell me that things had changed for the better.

Using a model from the literature search and field work, these examples can be summarised.

Table 4 Outcomes important to unpaid carers

Quality of life for the cared for person	Quality of life for the carer	Managing the caring role	Process
<p>A better access to opportunities for respite</p> <p>Greater financial security</p> <p>More allied health and medical care to improve the quality of life for the cared for person</p> <p>The ability to get assistance in both the daily tasks of personal care and advocacy for improving living circumstances in particular the suitability of housing arrangements.</p>	<p>A better access to programs for maintaining health and well-being</p> <p>A life of their own/independence</p> <p>Positive relationship with the person cared for</p> <p>Freedom from financial hardship</p> <p>Less of a sense of feeling isolated</p>	<p>Choices in caring, including the limits of caring</p> <p>Feeling informed/ skilled/equipped</p> <p>Satisfaction in caring</p> <p>Partnership with services</p>	<p>Valued/respected and expertise recognised</p> <p>Having a say in services</p> <p>Improved continuity of care for the person</p> <p>Flexible and responsive to changing needs</p> <p>Positive relationship with practitioners</p> <p>Accessible, available and free at the point of need</p>

(Modified from Stewart, 2008)

The Scottish framework of service user outcomes has elaborated these findings in a systematic way and covers three categories:

- *Quality of life or maintenance* outcomes which focus on trying to maintain the quality of life of the individual, despite sometimes deteriorating health (examples include feeling safe and social contact).
- *Change* outcomes that result from removing barriers to achieving quality of life, or reducing risks (examples include reduced symptoms such as feeling less depressed and improved confidence).
- *Process* outcomes result from the way in which services interact with people (examples include being listened to and feeling respected).

Quality of life or maintenance outcomes

Quality of life or maintenance outcomes may require varying levels of support over time and some might require support from sources other than health and social care services. They are:

- *Social contact* outcomes are where the person feels that they have enough contact with significant other people and that they have opportunities for social participation (to avoid social isolation).
- *Having things to do* is where the person has opportunities to undertake activities which interest them, both at home and outside the home including hobbies, voluntary work, education and employment.
- *Safety* is where the person feels safe and secure at home and in their community, including when they are using services. The person should be able to feel emotionally safe and able to rely on access to support when they need it, and where concerns exist, a risk assessment should be undertaken.
- *Staying as well as you can* is where the person feels that they are as physically and mentally well as they can be, given any illness or condition they have.
- *Living as you want/where you want* is where the person is able to plan and have control over their daily life and is able to live where they want.

Change outcomes

Change outcomes result from tackling barriers to achieving quality of life, or from reducing risks, and for some people it may be possible to identify a point at which the change has been achieved or partly achieved, and the focus moves to maintaining quality of life. They are:

- *Improved skills* are relevant where staff are supporting the person to regain skills and capacities
- *Improved confidence/morale* is where the person is working towards dealing positively with changed life and health circumstances, and/or attitudes towards ill health and disability.
- *Improved mobility* is where the person is working towards improved ability to get around within the home and/or outside (includes access to equipment, adaptations, therapy, transport)
- *Reduced symptoms* is where the person is experiencing fewer symptoms, for example, feeling less depressed or anxious, improved sleep, improved relationships

Process outcomes

Process outcomes are defined within the Talking Points framework as the impacts of the way the package of service is provided, or how the person is treated by staff. They are;

- *Being listened to* is where the person feels that their views about their own situation are listened to by staff
- *Being treated with respect* is where the person feels that they are treated as someone who has a right to services and as a fellow human being who has individual needs
- *Choice/having a say* is where the person's views are taken into consideration in deciding on a care package, including the nature and timing of support
- *Reliability* is where the person feels that they can rely on staff to turn up when they say they will (or be notified if there is a change of plan) and do what they say they will
- *Being responded to* is where the person feels that services respond to their changing needs and that they can rely on services to respond if particular difficulties arise.

The pattern of the interview responses from carers suggests a number of areas where outcome indicators can help to make sense of their experiences from their point of view:

- Indicators of the quantity and quality of various models of carer respite resulting in more free time for the carer

- Indicators of improved continuity of care
- Reduced client and carer social isolation, loneliness and worry
- Positive changes in care recipient health and quality of life
- Indicators of the effects of financial burden that may be threats to the stability of caring arrangements.

Research on what is known about what works for carers was undertaken in a project on *Effective Caring* for the Department of Health and Ageing in 2006 (Williams and Owen, 2009). The discussion of the practice implications of the research concluded that Australian strategies for service improvement can have a strong (but still highly variable) base of evidence that could be promoted as a platform on which to build:

- There is a reasonable evidence base for the two main types of services currently provided (respite and counselling), although there is not much evidence (at the macro level) about the specifics (e.g. type, dose, etc)
- There is a reasonable evidence base on other interventions not usually funded/provided, e.g. education / psycho-education especially for carers of people with dementia, disability and for mental illness support groups. The overall evidence is promising and there is emerging evidence about new support models, e.g. support groups via telephone and video conferencing show promise as a strategy to support rural and remote carers. The evidence on support groups is sufficient to justify carefully evaluated pilots.
- There is a need to be clear about the goal of intervention, i.e., therapeutic versus prevention/protection goals. This requires good initial assessment and periodic re-assessment to determine if the goal of the intervention should change
- There is very little in the published literature about how to support young (adolescent) carers
- There is a clearer picture emerging, from longitudinal studies on 'transitions' into and out of the carer role, of factors that may help strengthen the capacities of the growing number of employed carers, many of whom are not linked into the service system.

This picture from the literature (Williams and Owen, 2009, p.44) points to a set of useful research questions that could be addressed over time within an outcome focused research program aimed specifically at better meeting the needs of carers.

It implies a range of strategies that include understanding why carers may not use services such as respite, getting information to people who may not identify themselves as carers, evaluating and promoting more personalised and flexible respite models and service arrangements, and research aimed at removing workplace disincentives for carers to continue in their caring roles.

The challenges in measuring outcomes for clients/consumers at the person-level

The synthesis of the lessons to date leads to the conclusion that the preconditions for outcome measurement are an episode concept (to provide the 'bookends' needed for repeated measures), a goal of care and client-centred, rather than service-centred classification.

Episodes of care are clear cut in care packages where the set of services comes to an agreed end or where the goal of care is regularly checked to see if it has changed. The client goals built into the ACCNA and the ONI-N are an example of a practical starting point; the assessor asks if assistance is required to:

- (1) Improve current level of function and independence after a recent acute illness/event
- (2) Improve current level of function and independence (other)
- (3) Maintain current level of function and independence
- (4) Reduce rate of decline in level of function and independence

The assessor selects one goal only and records it in the client information system. The goal becomes one item in a pool of data elements capturing the salient characteristics of clients and carers that can subsequently be used for outcome measurement.

The pool of data elements can also be used to construct derived data items as prompts for particular service responses. For example the data in the final ACCNA report indicated how the relationships at the item level for the client's functional scores could be used for developing indicators of a client who might benefit from a program of rehabilitation.

This is where there is potential to link community care with the health sub-acute care agenda of developing a model suitable to ambulatory settings. Ambulatory rehabilitation can be either a continuation of an inpatient episode of rehabilitation into an ambulatory setting, or a rehabilitation program provided solely in an ambulatory setting. Ambulatory rehabilitation is not someone visiting outpatients for physiotherapy on an ad hoc basis, or similar (i.e. services are excluded if they are not part of a planned rehabilitation episode).

Implementation of the National Ambulatory Rehabilitation Benchmarking Initiative commenced in mid-2008. For Phase 1 of the initiative, AROC invited all current members to participate, via an Expression of Interest, to collaborate in refining the processes for data collection, analysis and reporting. Phase 2 will extend the initiative to cover providers of exclusive ambulatory rehabilitation services and those that are not currently members of AROC. An aim of Phase 1 was the streamlining of the data collection process allowing for a seamless transition to Phase 2.

Ambulatory rehabilitation is defined as:

- rehabilitation delivered in an ambulatory setting, either centre based or in the community
- the episode starts with a multidisciplinary assessment
- program of care designed around functional goals, short and long term
- program is time limited
- program of care is multidisciplinary, but therapies are not necessarily delivered concurrently

The Australian Modified Lawton's is also widely used by Home and Community Care Services as an assessment that can be reliably prompted from the HACC Functional Screening Tool. It has been shown to be valid and reliable, and as a generic outcome measure, successfully demonstrates changes in the ability to participate in activities of daily living as effected by their rehabilitation. The Australian Modified Lawton's is generally recognised as an easy tool to administer and requires minimal training.

The Australian Modified Lawton's measures rehabilitation outcomes in a broad context across the spectrum of care and service delivery models. As such, it is not designed, or intended, to replace existing service specific outcome measures, but is an additional tool used collectively to enable benchmarking. It is possible to browse through version 1 of the AROC Ambulatory Data Dictionary and Guidelines, including data collection proforma (http://chsd.uow.edu.au/aroc/ambulatory_dataset.html)

When discussing the logic of this classification and goal-setting approach in rehabilitation in the field, community care agencies pointed out parallels with the 'wellness' or 'enablement' agenda that is evolving in the HACC program. This was referred to in the HACC Annual Report (Home and Community Care Program 2009, p.37) and implies greater attention in future to the full continuum of needs in the community, not just the high need end or the provision of basic domestic support.

In investigating one agency's wellness centre (UCA) an interview was included with one of the centre's participants to understand what this more active service model means in practice. The informant was not a 'community care' client in the traditional sense, but was relatively fit and well

and was using the centre (a re-designed aged care day centre) as personal prevention strategy and a way to improve her strength and flexibility.

The preventive goals that were set were very specific to the results of an assessment, being the monitoring by the centre, with the support of her GP, of her blood pressure, flexibility and body mass index. These were self-monitoring methods formulated in negotiation over the goals she wished to achieve in attending the centre. The secondary aims were to extend her capacity for independent living in her own home as long as possible.

Similar outcome measurement challenges were articulated in a meeting with case managers in a community care agency undertaking a best practice project funded by ADHC (CCNB and its *Enable Me* program). That particular program is being evaluated and will provide guidance on the practical ways to manage the issues of broadening the client base for community care to better accommodate the wellness/prevention dimension.

The Victorian experience with the HACC Active Service Model is in its implementation period and no evaluations of the models are yet completed. There is similar work in Western Australia on independence programs by the Silver Chain organisation, called the Personal Enablement Program (PEP) (<http://www.silverchain.org.au/independence-programs/>). Silver Chain's PEP is a time-limited program (up to eight weeks) aimed at improving well being after a period of time in hospital and operates in addition to normal home care services.

As part of the broader English adult social care policy agenda, personalisation in the form of 'home care re-ablement' is currently high on the agenda. It aims to help people regain skills and confidence so they can live as independently as possible, and this in turn is linked to reducing their needs for longer-term home care services. However, in the UK as in Australia, it was noted in a report on the long term research program by the University of York group who are investigating the impact of these services, that little is known about what re-ablement involves or how best to organise services around these goals (Rabiee and Glendinning, 2010).

These findings mean the use of tools like the HACC functional screen will have to be supplemented with other tools to get around the ceiling effects for assessing those 'wellness' program consumers who are going to include those who are less functionally dependent.

The functional screening tool has been standardised using an Australian adaptation of the Older Americans Resources and Services (OARS scale) (Fillenbaum 1988), which has been shown to have some predictive validity beyond function and is routinely collected. Essentially serving as a set of prompts, these MDS items suggest assessment pathways, and these pathways can be automated to some extent when backed up by algorithms built into client management systems.

Computer adaptive testing (CAT) is an outcome measurement approach that can address these issues of 'ceiling and floor' effects in particular tools (Jette et al 2007). The development of item banks for each outcome of interest is a prerequisite to the development of CAT platforms. Each "test" is tailored to the unique level of each person because the items are administered on the basis of the person's previous responses.

This is similar to the logic of the modular assessment approach taken in the ACCNA, ONI-N and the ONI-IAM projects which attempts to avoid the administration of a large number of questionnaire items, by selecting only those questions from a large "item bank" that provide the maximum amount of information based on a person's responses to previous questions.

Systems for priority rating that use the functional screen and other items are like a triage function and represent one example of work that has a capacity to move towards a more sophisticated classification approach that can be used in allocating clients to programs and predicting the utilisation of resources.

The Post School Programs system uses the screen as its 'Functional Overview' tool and is an example of building a cost-related classification which is used for allocation purposes. The piloting of its use with young people with disabilities in Victoria has shown ways to automate and individualise the results of the assessment in a report giving feedback on their capabilities to the young people and their carers.

Measuring outcomes for providers at the agency or organisational level

The reporting of program outputs or outcomes by community care case management agencies in NSW was surveyed in a recent study that involved 'mapping the landscape'. Agencies identifying that they reported 'service centric' outputs were 75% of the sample, whereas those reporting on goal achievement were 20%, carer outcomes 14% and psychosocial outcomes 12% of the sample (See Simpson-Young and Fine, 2010, Table 37: Program output or outcome reported as currently being measured). So there is clearly a basic level of experience in current practice on which to build.

The consultations in the current project indicated a willingness for agencies in the field to work together towards a common approach. A number of agencies, particularly in the 'best practice' sites, were already sharing their experiences with more evidence-based outcomes measurement tools.

They pointed to the need to standardise data collection in a meaningful way by linking outcome measurement with 'the things that you do in practice', to inform care planning and case management, with practical tools to support decision-making with clients and carers. By feeding back data at the agency level, from a central collection point and within agencies to individual workers, it was eventually going to be possible to create an environment where continuous improvements in practice become possible.

Agency informants felt that providing feedback through data on client characteristics and outcomes, although complex to implement because of the culture change involved, would benefit ADHC program management by supplementing the 'process-oriented' quality improvement initiatives through systems of standards and accreditation. Linking aggregated client information with regional demographics and service provision information would give agencies the capacity to look for their own solutions.

The agencies were already attempting to get a better understanding of the needs of their clients through survey methods. Evidence derived from routine assessment data was expected to be more powerful because it could be managed at the agency level and give a basis for analysing where clients receiving different types and levels of services, may be experiencing different outcomes.

This current CHSD ADHC research project provides a synthesis of the lessons learned to date and a context for understanding what those lessons mean. The logic of using those lessons implies three levels of action, as consumer level data has to be able to be aggregated up to inform agency and program-level managers, on the assumption that it is more useful to have routinely collected client data used and re-used at other levels.

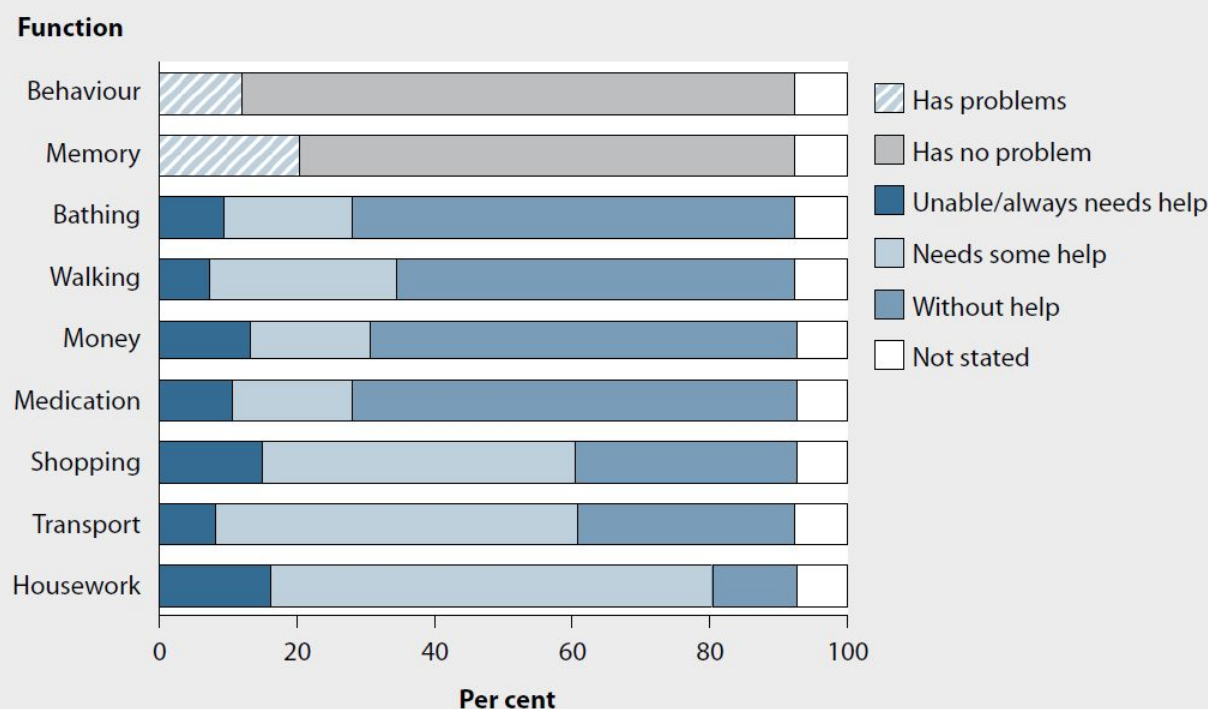
Measuring outcomes at the system or program level

The centrality of functional measures has been recognised and functional abilities are capable of being measured at the level of individual needs through to reporting at the level of the HACC Program in some jurisdictions.

However, the ability to use the data is limited, for example WA has produced a profile (see Box 3.6 below reproduced from the report by AIHW 2009, *Australia's Welfare* pp. 116-117).

Box 3.6: Need for assistance among HACC clients in Western Australia 2007–08

Assistance with housework was the most commonly reported need (80% of clients in Western Australia), followed by shopping (61%) and transport (61%). Personal care assistance such as with bathing and showering were needed by over one-quarter of clients (28%). HACC workers observed memory problems or confusion in 20% of older HACC clients, while behaviour problems were recorded for 12% of clients.



The profile reflects what would be expected in the program where domestic assistance, transport and shopping are the most common services provided and policy reflects the goal of providing basic services to clients with relatively low levels of need. A similar profile in packaged care cannot be produced, but the eligibility criteria for ‘packages’ programs would likely show higher levels of dependency.

But comparisons at program level are limited because of reporting issues, and in

“... 2007–08 no jurisdiction reported the functional needs of all HACC clients ... at least one functional item was reported for 466,000 clients” ... “Current reporting of functional needs is most often associated with the provision of assessment, case management, care coordination and counselling, in line with the recommendation that the care recipient’s functional status be rated at the start of a service episode or when there is reason to believe care needs have changed.”
(AIHW 2009, *Australia’s Welfare* pp 116 and.117).

A small but growing amount of local research is being commissioned by ADHC on ‘best practice’ models and when completed, the lessons from that research should be available to support reform of service models more generally and to provide a basis for more systematic research in the sector. To increase the amount of relevant research evidence, ADHC needs to build formal partnerships between researchers, policymakers, program and service managers and service

providers. More targeted investments in community aged and disability services research should aim to increase the use of routinely collected data for research.

However, as Adair et al. (2006) pointed out, there is a dynamic tension between the need for locally meaningful and strategic measures and the benefits of selecting and using standardised measures that enable meaningful comparisons.

That review of performance measurement in the public sector and business literature pointed out that the choice about what *not* to measure is as important as what to measure. What is not measured is generally considered of less importance, and that underscores the value of carefully selecting the most useful outcome measures. It was also noted that 'once collected, measures are rarely deleted, even if they are obsolete, and given limited resources, each measure chosen represents an opportunity cost'. (Adair et al.2006, p.64)

Appendix 5: A recommended development pathway

Developing a common approach during a period of transition

As the roles and responsibilities of program managers change there may be an opportunity to develop a common approach to outcome measurement in community care that can be consistent across the requirements of the National Healthcare Agreement and National Disability Agreement.

The Commonwealth will be responsible for regulating and funding basic community care services and packaged community and residential aged care for people aged 65 years and over as well as funding specialist disability services delivered under the National Disability Agreement for people aged 65 years and over and for Indigenous Australians aged 50 years and over.

The States will be responsible for regulating specialist disability services (as currently), as well as funding and regulating basic community care services for people under the age of 65 years. The States also be responsible for funding packaged community and residential aged care for people under the age of 65 years. (NHHN Agreement Appendix 3, clauses 13-15)

The NHHN Agreement says the Commonwealth and States will share responsibility for providing continuity of care across health services, aged care and disability services, where the aim is to ensure smooth client transitions. This exploratory study makes a case for outcome measurement being one way of achieving that aim, and that is reliant on better ways to classify clients, based on their goal of care and the main characteristics that drive their need for care and support.

These decisions reflect the long term aim to simplify the complex systems of health and community care from the point of view of service users. The proposed reforms will require a coherent approach within and across agencies where the implications will go beyond the level of the separate programs and the different sectors of health, aged care and disability.⁵

- The period from 2010 to 2011 represents the timeline to determine the scope and arrangements for the transfer of agreed services to the Commonwealth.
- In December 2010 COAG is to consider the possible transfer of community health promotion and population health programs including preventive health, drug and alcohol treatment, child and maternal health and community palliative care services.
- In July 2011, the Commonwealth takes full funding and policy responsibility for GP and primary health care in Australia.
- During 2011, COAG is to consider the possible transfer of specialist community mental health services.

The specific implementation arrangements include the planning and management of the transition of responsibilities between programs, and by implication the design of the interfaces between community aged care and disability services (NHHN Agreement Appendix 3, clauses 9a and 9b). This is where some of the details included in the current review of outcomes-based models can be most relevant.

As part of the National Disability Strategy, the Australian Government has commissioned an Inquiry by the Productivity Commission into a National Disability Long Term Care and Support Scheme for people with disability in Australia. The scope of the review is to assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

⁵ See <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/home>
http://www.dadhc.nsw.gov.au/NR/rdonlyres/CD3588A6-5D12-4B2E-A189-B28C648038FC/5248/Factsheet_COAGagesplit.pdf

- Provides long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking account the desired outcomes for each person over a lifetime;
- Is intended to cover people with disability not acquired as part of the natural process of ageing;
- Calculates and manages the costs of long-term care and support for people with severe and profound disability;
- Replaces the existing system funding for the eligible population;
- Ensures a range of support options is available, including individualised approaches;
- Includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime;
- Assists the person with disability to make decisions about their support; and
- Provides support for people to undertake employment where possible.⁶

The inquiry into the feasibility of a national disability insurance scheme has been widely welcomed by advocacy groups⁷ who see it as a way to improve the flexibility of the service system, provide more control by people with a disability and their carers over service models and create incentives to focus investment on both long term care and support and early intervention.

Continuity issues

Concepts of continuity across programs and service types are highly relevant during the transition period for the reforms in the different sectors of aged care, disability, primary care and the acute health care sector. These concepts have been investigated but remain a challenge in relation to performance measurement for program managers (Adair et al. 2006, p.64).

'More emphasis is needed on the development and application of direct measures of continuity from the patient's perspective and to measure continuity across organizational boundaries.' (Reid et al. 2002, p. i)

Haggerty et al. (2003), in a multidisciplinary review of continuity of care, distinguished three areas where continuity is important for service users in a way that may assist thinking about the reform challenges ahead for agencies at all levels:

- *Informational* continuity means information on prior events is used to give care that is appropriate to the patient's current circumstances. Using information on past events and personal circumstances is central to a more individualised approach in order to make current care appropriate for each individual.
- *Relational* continuity recognises the importance of knowledge of the patient as a person; an ongoing relationship between patients and providers is the under-girding that connects care over time and bridges discontinuous events. Coordinated approaches across programs imply an ongoing relationship between a person and one or more providers Casemix, multi-program, multi-disciplinary intake & assessment tools
- *Management* continuity ensures that care received from different providers is connected in a coherent way. Management continuity is usually focused on specific chronic problems or disabilities where a more consistent and coherent approach to the management of a person's conditions may encourage care that is responsive to a person's changing needs.

In a review of a program of research at the University of York, continuity of care was defined as something *experienced* by patients and their carers. As a complex, multi-dimensional concept, it was described as an *outcome* as well as a *process* of care. 'Hence, there was emphasis on the

⁶ <http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/tor.aspx>

⁷ See <http://australiansmadashell.com.au/index.html>

need to measure both patients' experiences of continuity ... and the difference continuity makes to their health outcomes as well as satisfaction with care.' (Parker et al. 2010, p.3)

'Despite continued attempts to alter policy and change practice, the ability of health and social care systems to deliver the type and level of continuity of care that service users desire remains in question. Lack of clarity about what continuity of care actually means, as well as imperfections in systems to deliver it, have been identified as part of the cause of this problem. (Parker et al. 2010a, Abstract)

The recommended ways of promoting continuity between sectors implies an approach during a period of transition that should start with initial agreement on a common interest in, and shared understanding of the value of, adopting a common outcomes-oriented classification approach. The current health reforms imply that the recommended development pathway will be relevant as a guide as community care programs make their transitions towards new national arrangements.

Reasons to proceed

In summary, there are four important reasons why the concepts of goals, classification and outcome measurement are important to the community care and disability services sector:

- The first is that the community care sector is so complex. It deals with so much information that we need to organise it in a coherent and logical way.
- The second is because what the community care sector does is important. It is critical to be able to measure need, monitor changes over time and be able to assess value for money and not just cost.
- The third is that a classification can act as a "common currency" between providers, funders and other stakeholders. Even though imperfect, this has helped the health industry and would help the community care and support sector as well.
- And finally, because the community care sector is so diverse, measurement tools are required which help to understand this diversity.

In the review of previous CHSD work we explained how the introduction of routine and standardised measurement of functional abilities constituted an important first step on a development pathway leading to a comprehensive client classification system for community care programs. It is then possible to use that classification to measure individual client need and also inform program-level and resource allocation decisions.

This implies the requirement to adopt a common approach to implementing standardised tools and establishing an incremental development pathway, with each stage being seen as a new 'generation' of an increasingly refined measurement suite for a mix of programs. As each new generation is developed it would progressively include more useful variables for classification purposes.

Recommended steps

Policy and program managers within ADHC should agree on a common process to progress the issues identified in this project and a timetable for their resolution, so as to improve the system's capacities for measuring outcomes⁸. It is not useful or cost-effective for different programs to design their own (inevitably different) outcome measures and client and carer survey and

⁸ *Stronger Together* policy document p.30: "Improved outcomes from our investment in Stronger Together. We will use what we learn from research, evaluation, consultation and performance monitoring to guide implementation. We will regularly review the mix of new services we fund as we find out which ones obtain the best result."

assessment tools. Without more standardisation in the approach it is inevitable that 'a thousand flowers bloom' and costs increase in the longer term.

The agencies consulted during the exploratory study suggested that an ADHC outcome measurement research and development strategy and work plan can be developed that builds on current best practice and does not have to start from scratch. The strategy should be jointly developed by program managers and agencies involved in developing best practice models, so as to be able to make the best use of the experience of community care agencies in the field.

Within ADHC the main outcome measurement issues for initial agreement are:

- The common interest in, and shared understanding of value of, adopting a common outcomes-oriented classification approach
- A suitable central point (across programs) from which to promote the adoption of a common outcomes-oriented classification approach to describing the capacities, needs and risks of clients
- The period of time over which need will be measured – i.e. the preferred ways to identify *episodes of care* to allow routine outcome measurement to occur within programs and across the community care sector.

The data elements in Appendix 2, along with recommended items on measures of social isolation, should be incorporated in CIS 2 to form Version 1 of a Core Community Care Data Item Pool for supporting outcome measurement, classification and information sharing across programs, service types and agencies. Most of the listed items are already in place as a result of previous work in this area.

Program managers and community care agencies should be given flexibility in adding any data elements they require for their own service provision and management purposes and in building in the core items to the 'front end' of their existing assessment and client management tools.

In addition to incorporating the data element pool in the NSW ADHC CIS2, a plan be developed for contributing to a nationally consistent approach how to promote this research and development work, including an education and training strategy. This will be important for efficiency of effort by way of sharing lessons and best practice, as well as efficiency from the client point of view. It could be either by progressive implementation on a jurisdiction-by-jurisdiction basis or by progressive implementation within a national intake assessment system.

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Glossary of terms relevant to outcome measurement

This exploratory study of outcome measurement in community care describes what is already understood and brings together an argument for a common set of concepts, methods and recommended data elements. It assumes that using a common framework of definitions and classifications can add value to many activities in the ageing and disability field and ultimately to the policies and services designed to meet the needs of people who are ageing or those with a disability.

The ageing and disability fields, like any major policy field, need information to inform debates about policy, desirable outcomes, and ultimately the best methods of resource allocation. Information is essential for effective decision-making and reform. And part of the information we need is quantifiable data that can paint part of the picture, tell part of the story but not the whole story, of what a person needs so that the service response can be more personalised.

Data provide a useful part of the story behind a person's needs, experiences and expectations of the services they may receive. Getting reliable and valid data relating to what services do and for whom and how they are experienced by users requires a common understanding of terms and how they are used.

This glossary has been prepared from a range of sources including the literature on research and evaluation frameworks, a glossary from Kent County in the UK called 'Jargon Busters', a glossary used in ADHC local planning workshops (Hunter Region), international sources including the World Health Organisation International Classification of Functioning, Disability and Health (ICF) (<http://www.who.int/classifications/icf/en/>) used by the Australian Centre for Clinical Terminology and Information (<http://chsd.uow.edu.au/accti.html>) and the Australian Institute of Health and Welfare METeOR system (<http://meteor.aihw.gov.au/content/index.phtml/itemId/181414>). It lists some of the common terms and concepts used in community care for the frail aged and people with disabilities, data collection systems, outcome measurement tools and evaluation.

Activities of daily living (ADL)

ADLs are personal care tasks such as eating/drinking, washing self, using the toilet, rising from a chair, getting in/out of bed, moving around indoors, dressing, walking outdoors. (ADLs are able to be routinely measured by standardised scales such as the HACC functional screen, the FIMTM and the Barthel scales and the are used for priority rating, service response classifications, resource allocation and planning the details of service provision)

Reference: <http://chsd.uow.edu.au/glossary.html>

Carer

A person who supports and has most contact with a dependent older person or a younger person with a disability and is not paid for their work. **Reference:** <http://chsd.uow.edu.au/glossary.html>

A person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons (i.e. aged 60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months. Assistance to a person in a different household relates to 'everyday types of activities', without specific information on the activities. Where the care recipient lives in the same household, the assistance is for one or more activities of daily living.

Reference: <http://meteor.aihw.gov.au/content/index.phtml/itemId/320939>

Casemix

Casemix is an information tool involving the use of scientific methods to build and make use of classifications of patient care episodes. In popular usage, casemix is the mix of types of patients treated by a hospital or other health care facility (Eagar and Hindle 1994). Casemix is about the relationship between hospital's activity and costs, and makes use of data about classifications that are clinically meaningful and explain variation in resource use.

Reference: <http://nccc.uow.edu.au/faq/Index.html>

Classification

The act of distributing things into classes or into one (and only one) category of the same type. The act of forming a distribution into groups according to some common relations or attributes.

Reference: <http://nccc.uow.edu.au/faq/Index.html>

Community care

The activity of providing personal care, social support and health care to older people and younger persons with a disability in their own homes as an alternative to more institutional (residential or centre-based) forms of care.

Reference: <http://chsd.uow.edu.au/glossary.html>

Consumer (or self) directed care

Consumer (or self) directed care allows people to have greater control over their own lives by allowing them, to the extent that they are capable and wish so to do, to make choices about the types of care services they access and the delivery of those services, including who will deliver the services and when.

Reference: Fact Sheet; Consumer Directed Care (CDC) in Australian Government Funded Community Aged Care.

[http://www.health.gov.au/internet/main/publishing.nsf/content/DD302E07EC976EAECA2577140017014E/\\$File/Consumer%20Directed%20Care%20Packages%20-%20Fact%20Sheet.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/DD302E07EC976EAECA2577140017014E/$File/Consumer%20Directed%20Care%20Packages%20-%20Fact%20Sheet.pdf)

Data

Aggregated or collected information including facts, concepts or instructions, represented in a formalised manner, that is suitable for communication, interpretation or processing.

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 47

<http://www.premiers.qld.gov.au/publications/categories/guides/criminal-justice.aspx>

Data Analysis

Systematically identifying patterns in information and deciding how to organise, classify, interrelate, compare and display it.

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 47

<http://www.premiers.qld.gov.au/publications/categories/guides/assets/criminal-justice-evaluation-framework.pdf>

Data Elements

A basic unit of information built on standard structures having a unique meaning and distinct units or values. In electronic recordkeeping, this is a combination of characters or bytes referring to one separate item of information, such as name, address, or age. In practice, data elements are sometimes "over loaded", meaning a given data element will have multiple potential meanings. While a known bad practice, over loading is nevertheless a very real factor or barrier to understanding what a system is doing, and ultimately what data analyses can reliably reveal and tell us about our programs or outcomes.

Reference: Beynon-Davies P. (2004). Database Systems 3rd Edition. Palgrave, Basingstoke, UK

Data Sources

Documents, people and observations that provide information.

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 47

Data Types

In information systems, and in [computer programming](#), these refer to the classification of a particular type of information. It is easy for humans to distinguish between different types of [data](#). We can usually tell at a glance whether a number is a percentage, a time, or an amount of money. We do this through special symbols -- %, :, and \$ -- that indicate the data's *type*. Similarly, a [computer](#) uses special internal codes to keep track of the different types of data that it [processes](#).

Most [programming languages](#) require the [programmer](#) to [declare](#) the [data type](#) of every data [object](#), and most [database systems](#) require the [user](#) to specify the type of each data [field](#). The available data types vary from one [programming language](#) to another, and from one database application to another

Data types become important when computers need to reliably process collections of information, collected from different sources or at different times. Humans will know for instance that a calendar date which is entered as 21/05/2010 refers to the 21st of May 2010. Dates such as 12/05/10 could be computationally interpreted as 12th of May 2010, or 5th of December 2010. Specifying - for programming and processing purposes – which type of date convention is being used (DD/MM/YYYY or MM/DD/YYYY or DDMMYY and so on) allows us to precisely and consistently analyse data collections (see Data Values, See also Data Analysis).

Reference: http://webopedia.com/TERM/D/data_type.html

Data Values

Formally, these are [specifications](#) for [values](#) of [data elements](#) comprising a [database](#), prescribed to [ensure data](#) consistency. Generally, and simply, these could be regarded as **answers**, providing information which tells us something about the patient, the client, the service or outcome. There is a wide range of data values which can be considered valid answers, and many will depend upon the definition of the data element (the questions). Some data values are coded (with numbers or identifiers) to better enable computers to process this information.

See also terminology, classification and codesets.

Reference: Truran D, Saad P, Zhang M, Innes K, Kemp M, Huckson S and Bennetts S (2009) *Using SNOMED CT® - enabled data collections in a national clinical research program; primary care data can be used in secondary studies*. Health Informatics Conference, 19-21 August 2009, Canberra.

Enablement/re-enablement

The terms re-enablement and enablement mean the same thing and are interchangeable. Re-enablement is part of the assessment process and is an intensive, short term service of four to six weeks designed to offer support to people, who by reason of injury, frailty or illness wish to regain or extend their independent living skills. Re-enablement is an essential element of Self-Directed support.

Reference: Kent County Council (UK), Adult Social Services – Jargon Buster

http://www.kent.gov.uk/adult_social_services/your_social_services/your_money/direct_payments/jargon_buster.aspx#individualbudget

Functional Dependency

A measure of functional dependency is an instrument that identifies areas in which a person requires assistance with daily living, and that quantifies the extent to which that person needs support from others to help them carry out normal activities in their home and community.

Reference: Professor Kathy Eagar, Janette Green and Alan Owen, Centre for Health Service Development (2010) *Functional Assessment of 2010 Post School Program Applicants* (training presentation)

Functional Hierarchy of Activities of Daily Living (ADLs)

People acquire and lose abilities in a predictable order. People acquire functional abilities in the opposite order to which they lose them. Self-care ADLs like dressing, toileting, feeding and bed

mobility are gained 1st and lost last (late loss ADLs). Domestic ADLs like housework, handling money, managing medicines are gained last and lost first (early loss ADLs). It is reasonable to assume that, if a person can do early loss ADLs, they can also do late loss ADLs. This forms a sound basis for screening.

Reference: Professor Kathy Eagar, Janette Green and Alan Owen, Centre for Health Service Development (2010) *Functional Assessment of 2010 Post School Program Applicants* (training presentation)

Functional Overview (Functional Screen)

Four domains are measured through 9 questions:

- Domestic functioning - 3 questions (housework, travelling to places and shopping) to screen for domestic function & 2 questions (handling money and taking medication) that also act as a screen for cognitive or behavioural problems
- Self-care functioning - 2 questions (walking, bathing)
- Challenging behaviour - 1 question
- Cognitive functioning - 1 question

Note the important item design feature of “Can Do (*not* Do Do)” – for example a person may be capable of taking medications even though they don’t have to, or may be able to shop even though someone else does it for them. Answers are limited to specific categories and the structure for the first 7 questions is the same:

Can do without help Can do with some help Cannot do

Reference: Kathy Eagar, Janette Green and Alan Owen, Centre for Health Service Development (2010) *Functional Assessment of 2010 Post School Program Applicants* (training presentation)

Goal

A goal is a simple statement which sets out the purpose of a program or evaluation. It is important not to confuse goals with objectives. An objective is a specific statement that can be measured.

For example the Australian Community Care Needs Assessment goals of care were to:

- (1) Improve current level of function and independence after a recent acute illness/event
- (2) Improve current level of function and independence (other)
- (3) Maintain current level of function and independence
- (4) Reduce rate of decline in level of function and independence

Reference: http://chsd.uow.edu.au/Publications/2007_pubs/accna_report07.pdf and Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 47

<http://www.premiers.qld.gov.au/publications/categories/guides/assets/criminal-justice-evaluation-framework.pdf>

Health Outcome

A change in the health of an individual, or a group of people or a population, which is wholly or partially attributable to an intervention or a series of interventions.

Reference: <http://meteor.aihw.gov.au/content/index.phtml/itemId/327238>

Health Outcome Indicator

A statistic or other unit of information which reflects, directly or indirectly, the effect of an intervention, facility, service or system on the health of its target population, or the health of an individual.

Reference: <http://meteor.aihw.gov.au/content/index.phtml/itemId/327246>

Health related quality of life

Like quality of life, this is an amorphous concept and a wide range of pertinent domains have been identified in the literature, including the perceived impact of health on optimum levels of physical, psychological and social well being and functioning, level of independence and control over life, and satisfaction with these levels.

Reference: <http://chsd.uow.edu.au/glossary.html>

Impairment

Is the anatomical or physiological damage caused by disease (for example, the reduction in cardiac output caused by ischaemic heart disease, or the restriction in joint movement caused by osteoarthritis). (See Impairment, Disability and Handicap).

Reference: <http://chsd.uow.edu.au/glossary.html>

Impairment, Disability and Handicap

The World Health Organisation (International Classification of Impairments, Disabilities and Handicaps. Geneva: WHO, 1980) made these important distinctions between the ways in which chronic diseases have an impact on the individual. This classification has since been revised to Impairments, Activities and Participation as the terms disability and handicap may be viewed as stigmatising by some people. (World Health Organisation ICDH-2. Geneva: WHO, 1998).

Reference: <http://chsd.uow.edu.au/glossary.html>

Instrumental activities of daily living (IADL)

Household, rather than personal, management activities: preparing meals, bed making, laundry/ironing, managing money, using the telephone, shopping and heavy housework.

Reference: <http://chsd.uow.edu.au/glossary.html>

Implementation

Implementation can be considered either as stages of implementation or implementation fidelity, i.e. the degree of implementation. Stages of implementation are exploration and adoption, installation, initial implementation, full operation, innovation and sustainability. Some care needs to be taken because stages are rarely a linear process. Conclusions on the outcomes of an intervention are problematic if there are no data about how well the intervention has been implemented. An effective intervention will not produce good results if it has not been well implemented. Or, more typically, when outcomes are mixed, one way of trying to 'unpack' what is going on is to try and distinguish between a poor intervention that may have been well implemented and a good intervention that has been poorly implemented.

References: Carroll, C., M. Patterson, et al. (2007). *A conceptual framework for implementation fidelity*. *Implementation Science* 2(1): 40. Fixsen, D. L., S. F. Naoom, et al. (2005). *Implementation research: a synthesis of the literature*. Tampa, Florida, University of South Florida, Louis de la Parte Florida Mental Health Institute, The National Implementation Research Network

Input

The inputs to a program are the resources used to carry out the work. Resources can be financial, material or human. From a program management point of view it is important to be aware of exactly what resources are available to carry out the work.

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 48

<http://www.premiers.qld.gov.au/publications/categories/guides/assets/criminal-justice-evaluation-framework.pdf>

Monitoring

The continuous and systematic collection and analysis of information (data) in relation to a program or project that is able to provide management and key stakeholders with an indication as to the extent of progress against stated goals and objectives. Monitoring focuses on processes (activities and outputs) but also monitors outcomes and impacts as guided by an accompanying Evaluation Plan.

Reference: (Anne Markiewicz, p2).

Non-acute care

Non-acute care is care for typically, but not always, a frail older person, who does not actually need to be in hospital but could, instead, be cared for at home or in a residential aged care home. Non-acute care is usually provided in a hospital while patients are waiting for placement in

residential care, waiting for their homes to be modified or the services that they will need at home to be organised or when their carer needs a break (respite care).

Reference: http://chsd.uow.edu.au/documents/abf_information_series_number_6.pdf

Objective

An objective is a statement that describes something you want to achieve – the desired outcome of a program or an evaluation study. It is important that objectives are written so that they are SMART (*specific, measurable, achievable, realistic, time-bound*).

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 48

<http://www.premiers.qld.gov.au/publications/categories/guides/assets/criminal-justice-evaluation-framework.pdf>

Outcomes

'Outcomes' refer to the impacts or end results of services on a person's life. Outcomes-focused services therefore aim to achieve the aspirations, goals and priorities identified by service users – in contrast to services whose content and/or forms of delivery are standardised or are determined solely by those who deliver them. Outcomes are by definition individualised, as they depend on the priorities and aspirations of individual people.

Reference: Glendinning et al. (2006) *Outcomes-focused services for older people*, Social Care Institute for Excellence, University of York,

<http://www.scie.org.uk/publications/knowledgereviews/kr13.pdf>

Outcomes achievement

The overall result of applying the inputs and achieving the outputs, or the effect or change resulting from an initiative or program. Outcomes can have short, medium and long-term achievements: Short-term outcomes = first-order effects of the initiative, which generally include changes to participants or the community; Medium-term outcomes = second-order effects of the initiative, which can include changes to policies, plans and projects; Longer-term outcomes - third-order effects, or the ultimate impact that the initiative should achieve, which can include fundamental changes in the social, environmental, economic and governance priorities of the government. The longer-term the outcome, the more likely that it will have been affected by factors external to the program that is being evaluated, and the longer you may have to wait until the outcomes are able to be assessed. Depending on the time available for your evaluation, it may only be possible to evaluate short to medium-term outcomes. However, whilst the evaluation of the longer-term outcomes is more challenging, it is also important.

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 48

<http://www.premiers.qld.gov.au/publications/categories/guides/assets/criminal-justice-evaluation-framework.pdf>

Output

An output is a piece of work produced for a program. It is important to realise that an output is not necessarily the final purpose of a program. Outputs are usually things that need to be done in order to produce the desired result.

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 48

<http://www.premiers.qld.gov.au/publications/categories/guides/assets/criminal-justice-evaluation-framework.pdf>

Performance Indicator

A statistic or other unit of information that reflects, directly or indirectly, the extent to which an expected outcome is achieved or the quality of processes leading to that outcome.

Reference: http://www.aihw.gov.au/hospitals/glossary_0708.pdf

Program Assumptions

Program assumptions are the beliefs we have about the program, the participants, and the way we expect the program to operate.

Reference: Criminal Justice Evaluation Framework (CJEF) Guideline Manual p 48
<http://www.premiers.qld.gov.au/publications/categories/guides/assets/criminal-justice-evaluation-framework.pdf>

Program logic

Program logic distinguishes between a logic model (the only criterion for which is that it be logical) and a theory of change which explains causal relationships. Logic models are descriptive whereas theories of change can be either explanatory or predictive. One of the dangers of either is uncovering a logic (or theory of change) that doesn't actually exist, i.e. the act of trying to uncover the logic reveals a logic that wasn't there to start with. There may be some scope for incorporating logic models or theories of change in build a logical and consistent approach to measuring outcomes.

Reference: Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods*. Thousand Oaks, California, Sage Publications.

Realistic evaluation

The central idea in *Realistic Evaluation* is that 'an outcome is caused by a mechanism acting in a context' i.e. to understand an outcome you need to understand what the mechanism is and the context within which that mechanism is operating. To understand why a program 'works' it is necessary to understand why the mechanisms within the program result in the particular outcomes they do. Although conceptually quite simple this approach is difficult in practice because there are so many mechanisms within even quite simple programs.

Reference: Pawson, R. and N. Tilley (1997). *Realistic Evaluation*. London, Sage Publications

Rehabilitation

Formally defined as the action of re-establishing a person in a former standing with respect to rank and legal rights and, in the context of medicine, is concerned with reablement of a person through provision of a stimulating environment, and encouraging greater activity, participation and autonomy; and re-settlement either in the person's own home or in alternative, more sheltered accommodation. Often necessary for older people after a short acute illness.

Reference: <http://chsd.uow.edu.au/glossary.html>

Rehabilitation episode of care

An episode of care for rehabilitation is provided: for a person with an impairment, disability or handicap and for whom there is reasonable expectation of functional gain; for whom the primary treatment goal is improvement (not maintenance) in functional status. Rehabilitation is characterized by:

- an individualised and documented initial and periodic assessment of functional ability by use of a recognised functional assessment measure.
- an individualised multidisciplinary rehabilitation plan which includes negotiated rehabilitation goals and indicative time frames.

Reference: Centre for Health Service Development University of Wollongong (2000) *The Illawarra Coordinated Care Trial Model of Care: defining consumer needs, community care interventions and care packages*. Plan for the 2001 Trial prepared on behalf of the Steering Committee.
[http://chsd.uow.edu.au/Publications/pre2001_pubs/defining_consumer_needs CCT_model%20of%20care3.pdf](http://chsd.uow.edu.au/Publications/pre2001_pubs/defining_consumer_needs_CCT_model%20of%20care3.pdf)

Self Directed Support

Self Directed Support is the process by which the individual has choice and control over the support they need to live their life as independently as possible. This may mean that they self manage the support, but they might also choose to have somebody else (including service providers or case managers) manage it for them.

Reference: Kent County Council (UK), Adult Social Services – Jargon Buster
http://www.kent.gov.uk/adult_social_services/your_social_services/your_money/direct_payments/jargon_buster.aspx#individualbudget

Sub-acute and Non-acute Care (SNAP)

The Australian National Sub-acute and Non-acute Patient (AN-SNAP) classification system was developed by the Centre for Health Service Development, University of Wollongong in 1997. The system has been periodically reviewed by clinical sub-committees comprising clinicians from sub-acute services to recommend changes to subsequent versions of the classification. The system has been designed to link with community care. For example, the AN-SNAP community classification uses five generic variables: Case Type (palliative; rehabilitation; geriatric evaluation and management; psychogeriatric; or maintenance or support); assessment only or intervention episode; age; provider type (sole practitioner or multidisciplinary); and self-care function. AN-SNAP also incorporates variables that are specific to particular Case Types. These are: phase (palliative; psychogeriatric); impairment (rehabilitation); and severity (palliative; psychogeriatric).

Reference: Eagar K. et al (1997) *The Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP): report of the National Sub-Acute and Non-Acute Casemix Classification Study*. Centre for Health Service Development, University of Wollongong.
http://chsd.uow.edu.au/Publications/pre2001_pubs/snapstudy1997.pdf

Terminology, classifications and codesets

Generally these might be regarded as a thesauri or dictionaries of terms (usually with codes) which can be used as data values. Many terminologies, classifications and codesets are developed and managed by 'authorities' to ensure that accurate meaning is represented, endorsed and is safely used in data collections. Examples are:

- The ABO Blood group typology. International Society of Blood Transfusion.
- The WHO Classification of Tumors affecting the Central Nervous System World Health Organisation
- ICD-10-AM (The International Statistical Classification of Diseases and Related Health Problems, Australian Modification (Australian Government Department of Health and Ageing, under license from WHO)
- SNOMED-CT; the Systematized Nomenclature of Medicine, Clinical Terms (International Health Terminology Standards Development Organization).

These authoritative sources of vocabularies provide data values and function as a standard reference, allowing different and disparate users to enter and collect data which everyone can share or exchange, access and understand. This helps make data collections usable and reusable for analysis of outcomes, performance indicators, public health monitoring, trend analyses of population health over time.

Reference: Truran D, Saad P, Zhang M, Innes K, Kemp M, Huckson S and Bennetts S (2009) *Using SNOMED CT® - enabled data collections in a national clinical research program; primary care data can be used in secondary studies*. Health Informatics Conference, 19-21 August 2009, Canberra.