

Home Care CDC Policy Elements and Guideline Development Advisory Paper

May 2013

One of the fundamental aims of the *Living Longer. Living Better* (LLL) reform package is to create a consumer led and directed aged care system. In its first year LLLB introduces a number of new CDC home care packages. By 1 July 2015 all packages, new and existing, will be CDC packages. In the longer term, the reforms will design and introduce CDC in residential care. Moving to a CDC based system is a fundamental shift from how services currently operate and to how consumers experience the aged care system.

The National Aged Care Alliance (the Alliance) has already provided advice to Government to assist in the introduction of CDC packages 'The National Aged Care Alliance advice on phase one development of Consumer Directed Care (CDC) Home Care Packages' prior to Government advertising their availability in the 2012 Aged Care Approvals Round (ACAR). A number of Alliance recommendations were adopted. The Phase One advice can be viewed at: http://www.naca.asn.au/naca-wg-login/home_care_CDC.html

Purpose of this Paper

The purpose of this paper is to provide advice to Government to:

- Further define the policy and principles underpinning Consumer Directed Care (CDC) packages; and
- Develop Program Guidelines and other information products.

An introductory section outlines the principles that should guide the delivery of CDC packages and be reflected in the development of the Program Guidelines.

The first section of the paper provides further policy definition and advice and is structured to reflect how consumers will experience the new Home Care CDC Packages. These steps include:

- Goal setting and care planning including a control and decision making framework, information and support;
- Individualised budgets including administration, core advisory and case management, service and support provision and/or purchasing, consumer fees and charges, package leave, package turnover;
- Service delivery including consumer/approved provider responsibilities, refusal of service provision, service inclusions/exclusions; and
- Monitoring, review, reassessments and evaluation.

The second section of the paper provides general advice around the style and content of various information products, including:

- Program Guidelines for approved providers;
- Information for consumers; and
- Other audiences.

The final section of the paper outlines other issues and areas for further discussion including:

- Transition;
- Interface with other programs;
- System gaps;
- Data collection;
- Resourcing
- Allocation of packages to special needs groups;
- Rural and remote;
- Assessment; and
- Disclosure requirements.

Specific questions posed by the Department are included throughout (*in blue italics*) for consideration.

The provider holding the package funding, and as a result having responsibility for case management, is referred to throughout the paper as the approved provider (AP).

Introduction

For the shift to CDC to be successful it is likely that many APs will need to significantly change their current processes and practices. Guidelines will be produced to support and encourage APs to make these changes. These guidelines should include the following principles for the operation and delivery of CDC packages:

Consumer Choice and Control

Consumers have managed their own lives for a long time. They should be empowered to continue to manage their own life by having control over the care and support they receive. This requires the provision of, and assistance to access, information about service options that enables consumers to build a package that supports them to live the life they want.

Entitlement

The CDC system should acknowledge older people's right, or entitlement (based on their assessed need), to the individualised services and support that will assist them.

Respectful and Balanced Partnerships

The development of respectful and balanced partnerships between consumers and APs, which reflect the consumer and AP rights and responsibilities, is absolutely crucial to consumer control and empowerment. Part of creating such a partnership is to determine the level of control the consumer wants to exercise. This will be different for every individual with some requiring or wanting assistance and others choosing to manage on their own.

Consumers should have an opportunity to work with the AP in the design, implementation, and monitoring of a CDC approach and cultural change in the AP organisation. APs should be encouraged to include consumers in their CDC redesigns.

Participation

Community and civic participation are important aspects for wellbeing. CDC in aged care should support the removal of barriers to participation for older people.

Wellness and Reablement

CDC packages should be offered within a restorative or reablement framework to enable the consumer to be as independent as possible, potentially reducing the need for ongoing and/or higher levels of service delivery.

Many people enter the aged care system at a point of crisis. Such situations may require the initial provision of services designed to address the immediate crisis. However, there should always be an assumption that the older person can regain their previous level of function and independence with reablement services being offered at a time that suits/supports the individual circumstances.

Transparency

Under a CDC system, older people have the right to use their budgets to purchase the services they choose. To make informed decisions about their care, older people need to have access to budgeting information, including the cost of services, the contents of their individualised budgets and how their package funding is spent.

Recommendation 1: Home Care Package Guidelines should incorporate the above CDC principles as requirements for all service provision.

Policy Definition and Advice

A. Goal Setting and Care Planning

The AP's role is to work with the older person to identify their goals and assist them in determining how they can achieve them. Goal setting and care planning should be undertaken in partnership and emphasise:

- Consumer choice and control;
- Support for consumer decision-making;
- Wellness and reablement; and
- Maintenance of independence and continuation of participation in community.

A purpose statement that outlines why the package is being provided (*e.g. 'to maintain me at home as independently as possible'*) should be developed to support the decision making process. The statement should include examples of the types of services and support that can be provided.

Care plan development needs to be driven by the consumer in consultation with the AP and result in agreement on the:

- Goals to achieve (which meet the purpose of the package for the individual);
- Amount of control they will exercise over package management;
- Services and support to purchase; and
- Provider/s who will provide the services and support (including specialist providers for those with special needs).

A Control and Decision Making Framework

Consumers (with their carer/family) should have ownership over decision-making. The consumer elects the level of control they have over the package from no active direction through to full direction. The desired level of consumer control may vary over time and systems should be in place to allow this to change as required. In some cases, this will mean that the AP role will undergo very little change, but in others the AP role will be to support and facilitate access to services rather than to directly deliver all of what the consumer requires.

The determination of who has the authority to make decisions (e.g. the individual consumer, a guardian, or a person with power of attorney) will be a crucial part of this process. APs will need to have a formal system to determine who has the authority to make decisions consistently and fairly. Such a system should also enable and support shared decision-making and duty of care between the consumer, their appointed representative (if they elect to have one) and the AP.

This will be particularly important in situations where the older person has a cognitive impairment. Cognitive impairment should not directly or automatically restrict the person taking control of their package but assistance may need to be provided to enable this to be realised.

Information and Support

CDC will require consumers to make informed decisions about how to use their resource allocation to achieve reasonable goals. In order to make these informed decisions, consumers need access to good quality, accessible, and understandable information.

Information should be available in a range of languages and accessible formats to ensure equity of access for consumers.

The Gateway, government, APs and consumer advocates all have a role to play in providing this support and information, which should include:

- General and standardised information, developed by government and made available at the initial contact through the Gateway and AP, which would explain:
 - o The CDC system and principles;
 - o The types of services and support able to be provided/purchased within packages; and
 - o Decision-making role/process.
- Specific information, developed and provided by APs, which would explain:
 - o Types of services and support available directly from the AP;
 - o Preferred provider list for service purchasing; and
 - o Organisations specific processes and policies in implementing CDC.

Consumers may also require a range of supports, including advocacy and peer support. The Alliance acknowledges that the LLLB package includes an expansion of such services, as well as an extension of the Community Visitors Scheme into home care services.

Information, linkages, and specific funding (outside of consumer packages) for advocacy services should be put into place to support consumers in a CDC system.¹

¹More detailed consideration of the development of, and access to, these supports may form part of the future work of the Advisory Group.

Recommendation 2: Care planning should have an emphasis on wellness and reablement, as well as maintenance of independence.

Recommendation 3: Consumers should have ownership of decision-making, including the amount of control they will exercise over package management at any given time.

Recommendation 4: APs should have a formal system to determine who has the authority to make decisions.

Recommendation 5: Consumers and their support networks should have access to good-quality, comprehensive and accessible information about CDC, the decision-making process, types of services and preferred providers, and inclusions/exclusions, as well as advocacy support to allow them to make informed decisions.

B. Individualised Budgets

The emphasis on transparency in the new system should encourage trust and understanding in the consumer/AP relationship.

The Alliance previous advice to Government has been adopted which means that:

- The AP will manage and administer the budget in a transparent manner meeting quality and accountability requirements; and
- Consumers will be made aware of their individual budget and receive a monthly statement of income and expenditure.

Transparency and consumer engagement requires the provision of budget information in a format that is simple for older people and their carers to understand. These statements should also be available in other languages and accessible formats as required by individual consumers.

It should be noted that the provision of individualised budgets in different languages and formats may have cost implications that require specific funding. Alternatives may include the provision of translation services and assistance in reading individualised budgets.

Defining and establishing the Individualised Budget

The Government subsidy will be defined by the package level (1-4), and be fully disclosed to the consumer. The total of the individualised budget will be made up of Government subsidy, consumer fees, and value of supplements. The budget will be separated into three components:

- Administration costs;
- Core advisory and care management services²; and
- Service and support provision and/or purchasing.

There will, at least initially, be variations in the amounts of funding allocated to various budget components by different providers with some providers costs varying greatly due either to regional variations or to supporting people with special needs (e.g. homeless, people with disabilities, LGBTI people, or CALD consumers).

² The costs of both administration costs and core advisory and case management services should be related to the agreed level of control being exercised by the consumer, the complexity of the arrangements (e.g. purchasing from multiple providers may be more expensive to administer) and ensuring the AP can appropriately support and inform consumer decisions.

Consumers will be given information about their budget, which is based on their agreed care plan with the AP, and will discuss and direct its use in partnership with the AP.

Consumers will also be provided with their periodic budget limits (including an update of their progress through these limits). Any unspent amounts will 'roll on' into future budgeting periods.

³Consideration should be given to budgeting for ongoing goods/services to ensure continuity of supply when consumers are developing their care plans with the AP.

It is worth noting that consumers with the financial means may also choose to purchase services over and above what it provided to them through any of the package levels. These transactions would not be included as part of the individualised budget amounts (although some APs may choose to include them in the statements in a separate category) and would not contribute towards any consumer fee caps.

Administration Costs

Administration costs reflect the establishment and set up costs for the package and would also include the costs of meeting Australian Government quality and accountability requirements.

Administration costs include:

- Insurance and government reporting;
- Corporate overheads;
- Capital costs;
- Ongoing research and service improvement;
- Advocacy;
- CDC administrative overheads including staff and IT;
- Developing statements and other consumer communication;
- Establishing contracts with sub-contracted providers; and
- Setting up and cancelling appointments.

Administration costs are likely to be higher during the transition period and this should be acknowledged.

Core Advisory and Case Management Services

This category will include the costs of:

- Initial assessment,
- Set up costs,
- Periodic reassessments,
- Case coordination or management or
- Provision of support to consumers that elect to manage their package themselves.

The budget should describe and quantify what tangible services will be provided to the consumer, e.g. costs are based on personal and phone contact of X hours per week at \$Y per hour (or appropriate service unit); and specify when reassessments are to be conducted.

³This needs to be explored by DoHA in terms of what is possible under current accounting standards and requirements.

The AP incurs costs from the moment they start to interact with a consumer in the assessment and package planning stages. These costs are not currently recognised within package funding but are a legitimate cost that needs to be incorporated in this category.

The case management role cannot be sub-contracted to another provider, although the Alliance acknowledges that in certain situations (particularly for special needs groups or in rural and remote locations) this may be required, and should be allowed, in order to meet specific consumer needs.

Service and Support Provision and/or Purchasing

This category will include the cost of direct service provision. This will not support 'cashing out' or direct payment of funds to consumers at this stage.

It is important to note that, in some cases, service costs may only be able to be reported after provision has occurred (i.e. actual cost as opposed to a scheduled cost), particularly in rural and remote areas.

This section will also confirm the decisions made in the care plan about what services have been chosen to be delivered/purchased (e.g. nursing, domestic assistance) and the individual costs of those.

Service and support provision and/or purchasing could also include a contingency fund to ensure that packages are not fully expended should an emergency or unplanned event arise. Contingency fund amounts should be agreed upon and should roll over⁴ payment periods.

Consumer Fees and Charges

Consumer fees and charges are the only element of the budget for which the consumer is responsible. However, hardship measures are being developed to pay providers where a consumer is financially unable to pay their fees and charges.

Consumers may be asked to pay a basic care fee (a percentage of their age pension) and may be required to pay an income-tested fee for the package they receive. This income-tested fee will be determined by Centrelink. Assessment must occur in a timely way to prevent undue delays to service provision.

It has been suggested by the National LGBTI Alliance that package recipients that live together (and are both receiving packages) should be able to elect to effectively pool their resources by sharing costs of the services across their individualised budget.

In a situation where a consumer (who is assessed as required, and financially able, to pay) does not pay their fees, the service provider should be able to recover the cost of services already provided but not paid for. Fees can be recouped by withholding a portion of the subsidy equivalent to the value of the services not paid for, thereby reducing the consumer's individual budget for future services.

Continued refusal to pay consumer fees over a long period of time may lead to service termination and this should be stated in the rights and responsibilities documents and in the client agreement. The period of time will need to be defined and will be the subject of further consideration.

⁴This needs to be explored by DoHA in terms of what is possible under current accounting standards and requirements.

Package Leave

Consumers can currently take 28 days leave from packages. It is recommended, to enable maximum flexibility, that longer periods of leave can be taken. It is not uncommon for a consumer to take an extended holiday to visit family or friends. Funding should continue to be paid into the individual budget throughout the leave period.

Further consideration should be given to the use of these funds during the leave period (continuation of services, accruing until return, recovery of AP costs such as broken shift allowances, etc.). Consideration should also be given to whether or not the consumer will be required to continue to pay fees (full or partial) during the leave period, as is currently the case.

APs may organise to sub-contract services to another provider at the holiday location to allow the consumer to continue to receive care whilst they are away.

The Alliance notes that there are currently different leave arrangements for different packages and as part of the transition phase these will need to be unified into single leave arrangements for all packages in an equitable way.

Package Turnover

In a future entitlement-based system, the package funding would be provided directly to the consumer and therefore remain with them and be portable to any new AP they choose, but the current reforms do not enable this to occur. There is already a commitment in the 5-year review to consider moves to an entitlement model for aged care services.

The implementation of the current reforms requires a system to be put in place to provide advice and assist consumers to move between APs, as well as to address any financial disincentives this creates for APs. This should be a relatively straightforward process that gives respect to consumer's right to make this choice.

Within these short term arrangements, it is agreed that if a consumer changes package levels, but remains with the same AP, any unexpended funds should remain with the consumer. However, there are mixed views amongst Alliance members regarding a situation in which a consumer permanently leaves the package. Two options have been presented:

- The AP could retain any unspent funds accrued for that period, in order to offset the reform process and related costs (the use of these funds should be transparently reported); or
- Unspent funds could be retained by the consumer (reform costs could instead be offset as part of the establishment costs of new referrals).

There is agreement that where there are large amounts of unexpended funds (particularly when a consumer has been saving up for a particular purchase and is changing AP because of a higher care needs) it may be appropriate for the AP to make an arrangement to transfer them to the new AP. A simple process should be developed to support this transfer of funds between APs.

Longer Term Budgeting Arrangements

The component approach agreed for budget transparency is supported in the transition period and in the short term. The Alliance recommends that a unit pricing approach that creates a transparent price for the services delivered is adopted as soon as is realistically possible. This would enable consumers to compare different services and make more informed decisions. It also enables providers to develop their own pricing approaches. This approach is currently used quite commonly in disability services, as well as for other products.

Recommendation 6: Individual budgets should be transparent, available in accessible formats and languages, and monthly statements should include consumer progress through periodic spending limits.

Recommendation 7: Contingency funds should be available within individual budgets for emergencies and unplanned needs.

Recommendation 8: In the longer term, unit costing for services should be adopted.

Recommendation 9: Unexpended funds should remain with the consumer when they change package levels but remain with the same AP. In the short term, unexpended funds may, in certain situations, remain with the AP where the consumer moves to another AP (as a result of choice or changing care needs).

C. Service Delivery

How will the approved providers' obligations and responsibilities be different under a package delivered on a CDC basis? For example, if the approved provider is not able to provide the care or services requested by the consumer, what steps must the approved provider take to meet consumer's needs/requests? How far must the approved provider go to meet those needs/requests? What if the consumer wants to receive care, services or case management from a particular service provider (or individual) with whom the approved provider does not have a contractual relationship?

Consumer choice in service delivery requires access to information about a range of different services, providers, locations and scheduling options. This information needs to be provided to consumers in plain English and in ways that are accessible for them (i.e. linguistically and culturally accessible, and available in different formats). Consumer choices/decisions made will be recorded in their care plan.

Choice and Sub-Contracting Arrangements

In the current system it is not uncommon for consumers to already have a level of choice as some APs regularly purchase and/or sub-contract delivery of required services to external providers in order to meet the consumer's needs and preferences.

Where this occurs APs are already required to have appropriate contracting arrangements in place. Now that all APs will be required to offer choice of provider within packages it is recommended that a "preferred provider" list is developed. The list would detail the sub-contracting arrangements the AP has in place with a range of other organisations to support people's needs. It would extend consumer choice without requiring APs to contract an individual service to a provider with whom they had no other relationship.

APs should also endeavour to build relationships with organisations that specialise in special needs groups. In particular, some special needs groups may request or prefer service providers that work with, are capable of providing for, or are from, the same special needs group.

The AP remains responsible for service quality and the meeting of all regulatory responsibilities where provision is sub-contracted. Any compliance issues would be dealt with through robust contract management and ultimately contract cancellation if required.

It should be noted, that aged care regulatory requirements are not a requirement for services already being widely provided to the local community. For example, the requirements for police checks may not apply for all staff at a local gymnasium. The use of package funding to purchase such services should not then subject such organisations to these requirements. This should be made clear to the consumer before purchase and access of service occurs.

It is possible that, even where there are extensive sub-contracting arrangements, consumers may still request a different service or provider. The AP should try to meet any reasonable request. Although every effort should be made to accommodate consumer requests, it is important to avoid the introduction of additional 'red tape' and the excessive use of package funding to broker individual contracts.

Establishing a new service agreement (with an organisation not on the preferred provider list) may also pose a delay to service delivery, as well as an additional cost (sometimes substantial), and these should be transparently reported in the individualised budgets.

When a consumer wants to change provider or services, the AP should assist them in finding a new provider, and this process should be made as straightforward as possible.

Contracting to Informal Carers

Contracting service provision to informal carers, family members, friends or neighbours is not generally supported by the Alliance. It is noted that in some instances (in remote Australia or within some ethnic communities for example) this may already occur and should continue to do so where there is no other workable alternative. However, a number of issues must be considered where such arrangements are, or need to be, in place:

- Elder abuse safeguards;
- AP responsibility for service quality, including the need to include the informal carer in their employee/volunteer/sub-contractor systems;
- Legal responsibilities;
- Industrial implications;
- Insurance requirements;
- Workplace health and safety; and
- Qualifications and training required to provide certain types of care.

The Program Guidelines need to cover these requirements where such arrangements are in place.

Recommendation 10: Consumers should have a choice of services, providers, locations and delivery schedules. This may require sub-contracting of services with organisations establishing a preferred provider list.

AP and Consumer Responsibilities

The Program Guidelines produced need to provide clarity on the balance between consumer choice and AP responsibility. This needs to be done in a way that protects the AP's capacity to refuse requests in certain circumstances, but also in a way that does not hamper flexibility or consumer choice.

The package will be signed off between the consumer and AP with clear documentation of the elements for which the provider and consumer are responsible. This could be seen as a first step in the development of a joint or shared duty of care between the consumer and the AP. Such an approach is required in a system where consumers are able to determine expenditure of funds.

There is an existing charter of rights and responsibilities for community care but the introduction of CDC packages highlights the need for a number of additional or amended responsibilities to be included:

For Approved Providers:

- Establish a positive and respectful partnership relationship with the consumer;
- Create and encourage space for a consumer to be creative in their care planning;
- Focus on consumers' health and wellbeing;
- Focus on reablement and avoid the assumption of inevitable decline;
- Provide access to information and education (both AP and independent) to support choice and decision-making;
- Offer choice of support, including choice of provider, service, timing and location;
- Create shared expectations without pre-determining certain outcomes;
- Respect the decision-maker and carer authority;
- To engage with carers as partners in care in line with the Carers Recognition Act (2010);and
- Respect relevant policies, protocols and laws.

For Consumers:

- Appreciate that the more clarity, openness, and honesty there is about needs, strengths and desires, the better the care plan and outcomes;
- Establish a respectful relationship with paid care workers;
- Be as clear as possible about who has decision-making authority;
- Be clear about the level of control (at any given point of time) that they wish to assume;
- Plan ahead (assign guardians and power of attorney, make arrangements for assisted decision-making, and make advanced care plans and other arrangements);
- Be open to a range of service possibilities/options, including measures to increase wellness and independence; and
- Participate in, as a minimum, an annual evaluation and reassessment at a mutually agreed upon time.

In practice, what would happen if the consumer feels that their needs are not being met under a package or if the package is not being delivered on a CDC basis?

In order to prevent any misunderstanding about what can be delivered, thorough and clear information regarding the operation and limitations of packages (including the financial limitations packages) should be provided to consumers at the outset.

The AP will have a communication and conflict resolution system in place (including ensuring appropriate arrangements are in place with any service sub-contracted), which supports feedback and reporting.

Information on complaints processes (both the AP and the Government Complaints Scheme) should also be provided to the consumer and outlined in the consumer's Service Agreement. Complaint protocols should also be outlined in the Program Guidelines.

Consumer education and support (including linkages to advocacy programs) must be readily available.

There may be more complaints during the transition process as consumers adjust to and understand the new system. Any such complaints should be used to shape future system improvements and be considered as an opportunity to work towards the application of best practice across the system.

There should also be mechanisms in place for consumers to regularly monitor, evaluate and give feedback on the extent to which the AP is meeting the consumer's needs and assisting the consumer to work towards their stated goals. Some Alliance members have raised the possibility of the introduction of KPIs, or a similar measurement system, to assist the AP and consumer to easily identify whether or not the agreed support is being delivered to the extent that is required in an objective manner. Not all members support this suggestion.

Recommendation 11: The existing charter of consumer rights and responsibilities should be redeveloped to reflect CDC principles.

Recommendation 12: The charter of AP rights and responsibilities should also be incorporated in the provider guidelines.

Recommendation 13: Education, support, mediation and advocacy should be provided to consumers to assist them in the complaints process.

Refusal of Service Provision

What if the consumer's request is unreasonable or unrealistic, or would result in a reduction in basic care services in order to fund a more expensive activity (e.g. holiday or capital item)?

Packages need to be as flexible as possible for consumers. However, there needs to be a balance between flexibility, appropriate use of public funds and provider responsibility.

In line with CDC principles the majority of the Alliance view is that individual APs will need to be able to decide to refuse a consumer request and that this should be done on a case-by-case basis. However, the below elements could form part of a "reasonableness" test (which may include a cost benefit analysis) to provide systemic consistency to these decisions, rather than be at the total discretion of an individual worker or AP:

- Service may cause harm or pose a threat to the health and/or safety of the consumer or staff;
- Service is an illegal activity;
- The consumer's choice of provider is outside the AP's preferred provider list – and all reasonable effort has been made to broker an acceptable sub-contracting arrangement;
- The requested service provider will not enter into a contract with the AP;
- There have been previous substantial difficulties or negative experiences with the consumer's suggested provider;
- Services that do not have a strong evidence base or that have been shown to be ineffective (where a strong evidence base is unavailable, as in the case of some special needs groups, clinical recommendations from health professionals with population-specific knowledge should be sufficient); and/or
- Situations in which a consumer may want to go without clinical services (resulting in a possible compromise of their health and/or wellbeing) in order to save for a more expensive non-clinical service.

Services for special needs groups should be carefully evaluated by professionals with group-specific knowledge to reduce service refusals that can result when special needs are falsely determined to pose a health and/or safety risk.

In any situation where a provider is withdrawing a service, an explanation of when and why this is occurring should be provided to the consumer.

Recommendation 14: A 'reasonableness' test should be applied by the AP to determine if it is reasonable to refuse a consumer request.

Security of Tenure

The current Security of Tenure arrangement will continue to apply to packaged care. Given the inclusion of higher consumer fees the provisions need to be strengthened to enable providers to withdraw services where the consumer has been assessed as being able, and required, to pay fees but refuses to do so over a long period of time.

Inclusion/Exclusion Approach

As it would be almost impossible to create a fully inclusive list and any list will limit the thinking of both the consumer and any provider involved (as it does now), the Alliance's majority position is that package content should be defined by exclusion rather than inclusion with information provided on the types of services package on which funding can be expended.⁵ However, it is acknowledged that this approach has not been supported by Government at this stage. This could be problematic as consumers will be paying substantial fees to have more control and choice over their package and being restricted by the inclusions list, may lead to consumer dissatisfaction.

⁵CHA considers that packages should be defined on an inclusion basis with listed exclusions being limited and governed largely by principles.

What are the guiding principles as to what types of care services should be included and/or excluded from a package funded by the Australian Government?

Rather than specifying particular services or inclusions, the policy purpose of Home Care, as well as the desired outcomes for consumers and the decision-making principles, should be used to define and justify service provision. The policy purpose of home care should be that it assists the older person to:

- Live in their own home as independently as possible for as long as possible; and
- Continue to engage with and participate in their community in whatever way they choose.

In this context, services may be designed to compensate for any specific challenges or barriers preventing full participation.

Consumers outcomes include:

- Improved (or maintained) well-being and quality of life for consumers and their carers;
- Alignment of purchases with consumer's goals (including provision of evidence of how any unusual purchase supports the consumers goals);
- Maximum flexibility for individual circumstances including the short term or emergency use of funding on items which would otherwise be excluded (e.g. accommodation costs) while an alternative or solution is found;
- Living safely at home;
- Reducing or eliminating non-required emergency hospital admissions;
- Delaying or eliminating the need to enter residential care;
- Maintaining and enhancing family and social relationships;
- Maintaining or improving independence and mobility (including the use of short term therapies); and
- Encouraging social inclusion and participation in the community.

In communicating with consumers the policy purpose and outcomes could be expressed in a plain English statement such as:

'Services I choose to support me to remain living as independently as possible in my own home and to participate in my community'

Inclusions

What would be the implications for consumers, providers and the workforce of allowing nursing and allied health services to be part of all packages, particularly at Level 1-2 where existing providers may not have the staffing capacity to provide clinical care themselves, or where there is limited capacity to purchase clinical services from Level 1-2 package subsidies? Could it potentially impact on the ability of some consumers to access nursing or allied health services from other sources/ programs? How might this impact differ from state to state?

Government has decided to continue the current inclusionary basis for defining what can be provided in a package and allowing flexibility for service provision/purchase outside of that listing. The inclusions list should not be seen as exhaustive and provision/purchase should be individually based on what the older person needs to meet their goals.

Within this framework the current listing provides a reasonable starting point but the Alliance recommends the following additional inclusions across all four package levels to enable consumers to meet their goals:

- Nursing, allied health and other therapies, including specialist service providers.

It is acknowledged that it is unlikely that a consumer would use lower level packages for these services given the amount of funding available. However, it is not uncommon for a consumer to be given a lower level package than what is required due to lack of availability of higher level packages. In such cases, it may be that some clinical services are necessary and provided.

If regular clinical care is needed on an ongoing basis this may be a sign that the consumer needs a higher level of package, and might be considered a trigger for reassessment (discussed in further detail at page 18).

Potential jurisdictional charging/cost shifting issues need to be worked through, but should not be used as a means of restricting consumer direction or choice. A transitional arrangement would need to be developed with State Governments to ensure ongoing access to other relevant programs is not restricted due to package funding supporting these services. Interface issues, including with the HACC/DTC programs, need to be considered as the Home Support Program is being designed and implemented.

Assistive technology, such as aids and equipment (particularly those that assist a person to perform daily living tasks), as well as devices that assist mobility, vision, communication and personal safety.

Given the available budget, it is likely that the purchase of equipment will be limited in the lower package levels. However it should be possible in all package levels. Measures may need to be taken to ensure they are not excluded from other funding schemes on the basis that assistive technologies are covered by their Home Care Package.

Allowing purchase of aids and equipment with package funds requires issues of ownership and maintenance to be addressed. Maintenance (including cleaning and storing) needs to be included as a cost in the consumer's individualised budget. Currently these items generally remain the consumer's property and this should continue to be the case. If a consumer's needs change, they may want to sell their current assistive technology in order to partially fund the purchase of a new product that better suits their needs.

Assistive technology may include services such as video conferencing when that enables access to services that may otherwise be unavailable in rural and remote areas.

It should be noted that trans-gendered and intersex people's use of and need for assistive technology can often seem unnecessary to those without population-specific knowledge. Therefore, it will be important to ensure that such items will be covered.

Exclusions

If specific services or types/classes of expenditure are to be excluded, what are they?

Any exclusions used in the Program Guidelines should be minimal in order to allow service provision to provide the flexibility required by a CDC system. The Alliance supports the following specific exclusions:

- Use of package care funds to supplement income payments;

Home Care Packages are not designed to supplement the pension. This includes using package funding to pay the client co-contribution for services received as part of the package. Hardship provisions will be applied and cover circumstances where the person can't afford to pay.

However it may be that as a result of a clinical condition an individual consumer has higher utility costs that cannot be met from their income. Use of package funding can be considered in such circumstances on a case by case basis.

- Domestic and overseas travel costs (flights, accommodation);

Package funds should not be used for a consumers own travel or participation costs. However, package funds should be able to be used to facilitate holidays, travel etc. (i.e. assistance in planning, the continuation of care services in the holiday location, to address specific needs raised by being away from the home such as the rental of aids and equipment or provision of carer respite in holiday location), and/or staff attendance/support for the person to travel or participate in an event or function). There may also be certain circumstances where it would be appropriate to include travel costs in a package (such as an Indigenous consumer's need to return to country), and there should be flexibility in the system to allow this.

- Paying for permanent accommodation e.g. mortgage payments, rental, etc.;

Package funding shouldn't be used to pay for permanent accommodation in an ongoing way. However in a crisis situation, where the person would be evicted or become homeless, it should be possible to utilise funds while a solution to the housing issue is sought.

- Motorised wheelchairs and customised aids;

This is an area that will need future policy development to ensure that increasingly frail consumers have equitable and timely access to the aids and equipment they need to support independence. This may mean the hire/lease of motorised wheelchairs, and/or the development of a specialised aids and equipment scheme.

- Major home modifications that are not related to care needs;

There are many home modifications undertaken with community care and package funding that enable the older person to remain successfully at home. This can include bathroom and kitchen renovations, addition of ramps, increased or changed lighting for those with vision impairments, etc. However the guidelines must be clear that where such a modification does not support a specific care need it cannot be undertaken with package funding.

Other suggested exclusions:

- Attendance costs, and transport, to and from events in certain situations;
- Services and items covered under the Pharmaceutical Benefits Scheme (PBS), Medicare Benefits Scheme (MBS) or Repatriation Pharmaceutical Benefits Scheme (RPBS);
- Gambling;
- Illegal activities; and
- Non-care related capital items.

Recommendation 15: Service provision should be guided by outcomes, rather than specific in/exclusions. These outcomes should be reflective of CDC principles.

Recommendation 16: At all package levels, funds should be able to be utilised to provide or purchase nursing, allied health or other specialist services as well as assistive technology, aids or equipment.

Recommendation 17: Exclusions should be minimal to ensure flexibility and choice.

D. Monitoring, Review, Reassessment and Evaluation

There will be ongoing communication between the consumer, AP and aged care workers to identify and address any issues that occur. The monitoring, review, reassessment, and evaluation process should ensure that care plans evolve with changes in consumer needs and preferences.

It is important to note that there is a difference between review and reassessment functions.

Review is a continuous process between APs and Consumers to check if the consumer is happy with the services they are receiving. This process also supports the AP to meet all their compliance requirements. **Reassessment** is a more formal process that involves assessing the consumer's needs, goals and preferences in order to update their care plan and what services they receive if necessary.

In a truly consumer led service system reassessment would only occur at the clients behest with ongoing monitoring/feedback systems enabling providers to proactively manage risks and adjust the package as required.

However, given AP's various quality, legal and contractual obligations, there will be a need to maintain the practice of regular formal reassessment. There is a mix of views on the exact timing of the regular formal assessment. Some members feel that assessments should only take place at the consumer's request or when there is a significant event/change in needs. Other members feel that formal assessments should be required every 3 months. The majority of the Alliance position was for a minimum of an annual reassessment.

The cost of doing this would be included in the individual package budget, and should not be optional for consumers - i.e. they cannot opt out of the reassessment function.

The frequency and style of reassessments match consumer preferences wherever possible.

A range of reassessment triggers that may require an additional or earlier reassessment include:

- A health “crisis” or episode;
- The ongoing use of regular clinical services by a consumer on a level 1 or 2 package;
- Change in care need;
- Change in living arrangements;
- The use of a large amount (or entire) contingency fund; or
- Consumer request.

It should be possible to undertake more than an annual reassessment where this has been discussed with the consumer and documented in the client agreement.

All reassessments should have a reablement and wellness focus that does not assume decline, and would involve:

- Review of consumer goals;
- An evaluation of the quality and success of the supports that have been provided;
- A renegotiation and update of the care plan; and
- Support for the consumer to continue to make informed decisions.

It is possible that consumers, who initially declined or accepted to be actively involved in decision-making and management of their package, may change their mind and elect to do so at a reassessments. This option must be actively explored at each reassessment.

Reassessments should also be designed to allow consumers to move seamlessly between higher and lower levels of support.

In the majority of cases review and reassessment would be undertaken by the service provider. However the consumer should have the right to request that a reassessment be undertaken by the Gateway (from March 2014). Where such a request is made, the Gateway should undertake such reassessments face-to-face and this could be done via video linkage if required.

Recommendation 18: Reviews should be an ongoing process and involve reassessing goals, updating care-plans and supporting the consumer to make decisions.

Recommendation 19: Reassessments should be annual (at a minimum) but could be triggered earlier than this by health episodes, changes in care need, or a consumer request.

Recommendation 20: Consumers should be able to request a reassessment by the Gateway rather than having it done by their service provider.

The Program Guidelines and Other Information Products

Program Guidelines for APs

The fundamental shift that the introduction of CDC will make in the aged care service system should not be underestimated. The Program Guidelines need to be redesigned to reflect this. They should also be much shorter and more concise, use plainer language and contain a glossary of key terms.

The Program Guidelines are designed to be used by APs (in addition to government workers, quality auditors, ACATs and other industry groups). In the future, it is likely that staff of the Aged Care Gateway would also use these Program Guidelines.

Program Guidelines are designed to 'guide' rather than 'prescribe' action, and to be useful in a CDC system they should retain a level of flexibility to meet consumers' needs and preferences.

The core structure of the new Program Guidelines should reflect the consumer experience of CDC Home Care Packages:

- Goal Setting and Care Planning;
- Individualised Budgets;
- Service Delivery; and
- Monitoring, Review, Reassessment and Evaluation.

Information for Consumers and Carers

Multiple information products need to be available for a range of audiences, most importantly consumers and their carers. To allow access to relevant information for different people and groups (including special needs groups), all information products need to be developed in an array of formats, languages and over a range of technologies - including social media. Information for special needs groups should also include markers for services that specialise in specific needs.

There should be an attempt to retain consistency of headings and structure with provider oriented Program Guidelines and information wherever possible to allow cross checking between information products.

Information for consumers should be comprehensive, accessible, and written in plain-English. The simplicity and accessibility of such documents will be particularly important for the many people that enter the system at a point of crisis and need to find the most helpful support as quickly as possible.

These documents should be designed to assist consumers to navigate, and make informed choices within, the new system and packages. Products of this type may include:

- Scenarios/examples/stories;
- Brochures (what you can and can't do);
- Information about decision-making, frameworks, and assigning decision-makers;
- Peer support and advocacy information;
- Information about advanced care and end-of-life planning;
- Information about specialist service providers where consumer has a specific need or disability;

- Quality Indicators;⁶ and
- Information about consumer and AP rights and responsibilities.

Existing consumers will also need information that explains the transition from the existing packages to CDC. As different organisations will transfer to CDC at varying times in the lead up to the 2015 deadline, such information needs to be developed and available from 1st July 2013.

When such information products are available, it may be useful to hold some consumer forums and education sessions to explain the CDC concepts and new programs. This could be done by service providers and/or through consumer networks.

Other Audiences

There are a range of other audiences, who will also need information, including:

- General practitioners, nurses and allied health professionals;
- Pharmacists as distributors of information;
- Consumer representatives/advocates/informal carers;
- Providers – brokers / 3rd party providers;
- Government workers;
- Quality auditors;
- IT vendors;
- ACATS/Gateway; and
- Linked services – such as Medicare Locals, Hospitals.

Recommendation 21: Program Guidelines should be developed to fully support CDC implementation including reablement and wellness principles.

Recommendation 22: Program Guidelines should be structured to reflect the consumer experience of the Home Care Packages.

Recommendation 23: Accessible, plain-English information products should be accessible to consumers in a range of different formats, technologies and languages.

Recommendation 24: Information products for other audiences should also be developed.

⁶The LLLB reform package includes development of such quality indicators. The timeline for this work is not clear at this stage.

Other Issues and Further Work

Are there any other policy and implementation issues that should be included in the guidelines?

Transition

The LLLB package requires all new and existing packages to be provided on a CDC basis by 1 July 2015.

Individual APs will determine the most appropriate time to transition based on their clients, and organisations circumstances and requirements.

APs should be given the opportunity to convert their existing packages before 2015 if they are ready to operate on a CDC basis. A number of APs are already indicating a desire and intention to do this, particularly where they already have, or will receive, new CDC packages in the most recent ACAR.

It is suggested that during transition, APs consider grand-parenting arrangements for existing clients (particularly where they may transition to a lower level of package funding) and/or converting packages as clients turnover. Existing package recipients should not need to be reassessed by an ACAT when transferring to an equivalent level CDC package.

ACAT staff may require transition assessment training to appropriately assess consumers for the new package levels and system.

Consumers need to be provided with information so they understand the type of package they are receiving and the practical implications of that. There should be a process in place for consumers to request a CDC package, as well as advice for consumers who want a CDC package if one is not currently available.

The Department needs to determine a simple notification process for APs to advise when, and the numbers of packages that will be, converted to a CDC basis. Notification should not be required on an individual package basis as this would be unnecessarily burdensome. It would be better to advertise dates throughout the period (potentially at least twice per calendar year) when APs can advise the number of packages that are being, or have been, converted in that period. The process should allow for retrospective advice. This will enable the Government to monitor the process and ensure all packages are transitioned by 1 July 2015.

It should be noted that if a consumer elects to leave full control of the package with the AP that is still their decision and choice. Packages where the consumer makes this choice should still be seen as a CDC package as long as it was offered in line with the program guidelines (including meeting transparent budget and reporting requirements).

It will be critically important that resources and supports are put in place to:

- Assist organisations transition to the new system;
- Enable staff to be trained and supported in delivering CDC; and
- Ensure that consumers are equipped to take full advantage of the opportunities it presents for better quality of care and life, including provision of information to make choices.

Recommendation 25: A simple process of reporting twice a year, including retrospectively, should be established by Government to encourage and support APs who choose to convert existing packages to CDC ahead of the 1 July 2015 deadline.

Recommendation 26: Consumers should be provided with transition information, and a process should be established for them to request to transfer their packages to CDC before 1 July 2015. No additional assessment should occur as part of this process.

Recommendation 27: A change management approach, including identification and provision of resources and supports – for consumers, workers and providers, should be adopted to effectively establish and embed a CDC service system.

Interface Issues

One of the most critical interfaces to address in the immediate future is that with the existing HACC Program (currently being redeveloped as the Home Support Program). The HACC program will remain with the respective State Governments in Victoria and Western Australia rather than transferring to the Commonwealth aged care system. This will need to be an additional and specific consideration within these interface issues.

There needs to be a clear statement on the access package consumers can and should have to HACC/Home Support Program funded services. This is important to maintain the real value of lower level packages.

Consumers on a CACP packages can generally still access the nursing services provided by HACC (where there is availability) but nursing is included within the package for EACH consumers. Arrangements vary from state to state with the package funds required to pay (full cost) for HACC services accessed in some instances. This needs to be addressed now that both programs are under Commonwealth Government control.

These interface issues will need to be actively worked through. It will be difficult to do this until design elements in that program and in CDC packages are better defined. Those involved in designing these two programs are aware of the linkages required and the issues involved. The Alliance will establish a working group to examine the interface issues to provide further advice on this matter. It is recommended that in the interim the existing rules remain in place.

Other interfaces which need to be reviewed include:

- NDIS/disability services/younger people in residential aged care particularly in relation to those with disabilities and/those requiring specific services and the sixty five years of age cut off;
- DVA home care and nursing services;
- Aids and Equipment schemes;
- Medicare Locals; and
- The health system more broadly, including nursing, allied health, pharmacy, transitional care services, hospital services, geriatric services, outpatient clinics and complementary therapies.

Service Top Up

Consumers may receive services from a variety of organisations or programs. Currently, they may not want to reveal what they are receiving from another program in case the services are ceased. This may be a transition issue that can be addressed through:

- Partnership and CDC direction of home care packages;
- Linked consumer records, integrated assessment and care planning.

Providing information to consumers on what services are available combined with coordination of services across programs and complementary services to provide equity of access will be crucial to successful and effective service delivery.

Recommendation 28: Considerable work should be undertaken to ensure the successful and effective interface between the CDC Home Care Packages and other existing programs, particularly the current HACC (Home Support) Program.

Recommendation 29: Consumers on a package should continue to be eligible to access nursing, allied health or other specialist services through the HACC program (and its successor the Home Support Program). Guidelines in both programs need to clearly state the eligibility of package clients for these services.

System Gaps

A range of gaps in the current system that should be addressed in the new system include:

- Unit Pricing

In the longer term, the Alliance has recommended a move to unit pricing. An independent cost of care study would assist in moving to this approach.

A cost of care study should take into account the full costs of providing services in different geographical locations (e.g. rural and remote, as well as excessive costs sometimes experienced in expensive city centres), and to special needs groups. It should also take into account realistic indexation of packages.

Ideally, prices should be set to allow consumers to make informed decisions about which provider they may choose.

- Workforce Implications

Thorough modelling of the potential impacts on the workforce should take place and be evaluated to provide feedback in formalising the model before full system conversion in 2015. These impacts are likely to include:

- o Recruiting, retention and training issues;
- o The casualisation and de-skilling of workers;
- o The need to ensure pay to workers in a CDC system; and
- o The expanded costs of providing care at times chosen by consumer (may increase out of hours and weekend care).

- Quality indicators for community care

The LLLB reforms includes the development of quality indicators for community care, but the development of these is most likely 2-3 years away.

- Arrangements for special needs groups

This includes rural and remote areas, as well as smaller or specialised providers. It is unclear if the additional costs associated with the operation of targeted service provision (for example, translation services for CALD specific services) will be funded separately or will be included in the individualised budgets.

There is also a specific issue facing those over 65 with vision impairment, who may fall outside the NDIS, but may also face difficulties having their specific needs addressed within the Home Care CDC Packages. Consideration may need to be given to the creation of specialist pathways for vision-impaired consumers to access specialist vision services.

Rural and remote consumers are likely to continue to be disadvantaged as a result of the additional costs of delivery (often travel related costs). Although a viability supplement is paid, not all affected consumers receive it and it is inadequate to equalise the level of service able to be provided to individual consumers. The Alliance believes that there needs to be a higher level of compensation to ensure that consumers in remote areas do not continue to receive less service than their metropolitan counterparts.

Recommendation 30: An independent cost of care study should be undertaken to support a move to unit pricing.

Recommendation 31: Modelling the potential impacts of CDC implementation on the community care workforce should be undertaken and addressed prior to full implementation in 2015.

Recommendation 32: Additional costs associated with service provision to special needs groups (including CALD and rural and remote consumers) should be adequately recognised to achieve service delivery equity.

Data collection

The importance of accurate and thorough data collection and evaluation for future system review should not be underestimated and linkages between, as well as data standardisation across, programs should be considered.

Providers should report expenditure against service categories (potentially the existing EACH package headings) to provide data. This will be important, at least in the short term, for monitoring and evaluation of both CDC and package levels.

Resourcing

The introduction of CDC home care packages is the first step in a system wide transformation. Resources will be needed to support consumers to take full advantage of the increased control and flexibility and for aged care providers to make the cultural and operational changes to offer CDC. This may include increased advocacy services for consumers and one off system development and/or training grants for providers.

Allocation of packages to Special Needs Groups

A process should be in place to target and allocate packages to special needs groups, including those with disabilities, providers could also comment on their work undertaken for special needs groups. This used to occur as part of the ACAR but this requirement was dropped in the 2012/13 ACAR. This system should be reinstated for future rounds to provide opportunity for providers to reflect on their work practices as part of this process.

Assessment

Assessment is being considered at length in the work of the Alliance Gateway Advisory Group. Assessment for packages has been broad banded so that consumers require an assessment to access a level 1 and 2 package and then again to access a level 3 and 4 package.

There needs to be transparent decision making criteria and process to inform movement within the bands to ensure that allocation does not only occur on the basis of availability and that providers have flexibility within each range to address individual needs. A simple form of validation of package expenditure will be required and this should be included in the program guidelines.

In the longer term, the Alliance recommends that the assessment process for home care packages be streamlined so that there is only one major assessment of the consumer's needs with changes in circumstances and requirements (with access to more or less services) being managed by the consumer and the AP.

The LLLB package proposes the creation of an ACFI style assessment across the entire system to enable this to occur. While the Alliance believes there may be other appropriate assessment models to achieve this it is strongly supportive of the principle of an integrated and streamlined approach that better supports the consumer. It is acknowledged that this will take time to be developed and that an interim arrangement needs to be established.

Disclosure Requirements

It is not known if the current requirement in EACH and EACH-D packages for consumers to provide full disclosure of medical information to assist service provision will continue in the new system or be replaced by an arrangement that places consumer right to choice over the requirement for disclosure. The implications of not revealing medical information for adequate care provision may need to be explored if this is the case. It may make sense to include an acceptance of risk (or equivalent) document in cases without full disclosure, and this will be further discussed and developed in the future work of the Advisory Group.

Recommendations

In summary the Alliance recommends:

Recommendation 1: Home Care Package Guidelines should incorporate CDC principles (including consumer choice and control, entitlement, respectful and constructive consumer/AP relationships, participation, wellness and reablement, and transparency) as requirements for all service provision.

Recommendation 2: Care planning should have an emphasis on wellness and reablement, as well as maintenance of independence.

Recommendation 3: Consumers should have ownership of decision-making, including the amount of control they will exercise over package management at any given time.

Recommendation 4: APs should have a formal system to determine who has the authority to make decisions.

Recommendation 5: Consumers and their support networks should have access to good-quality, comprehensive and accessible information about CDC, the decision-making process, types of services and preferred providers, and inclusions/exclusions, as well as advocacy support to allow them to make informed decisions.

Recommendation 6: Individual budgets should be transparent, available in accessible formats and languages, and monthly statements should include consumer progress through periodic spending limits.

Recommendation 7: Contingency funds should be available within individual budgets for emergencies and unplanned needs.

Recommendation 8: In the longer term, unit costing for services should be adopted.

Recommendation 9: Unexpended funds should remain with the consumer when they change package levels but remain with the same AP. In the short term, unexpended funds may, in certain situations, remain with the AP where the consumer moves to another AP (as a result of choice or changing care needs).

Recommendation 10: Consumers should have a choice of services, providers, locations and delivery schedules. This may require sub-contracting of services with organisations establishing a preferred provider list.

Recommendation 11: The existing charter of consumer rights and responsibilities should be redeveloped to reflect CDC principles.

Recommendation 12: The charter of AP rights and responsibilities should also be incorporated in the provider guidelines.

Recommendation 13: Education, support, mediation and advocacy should be provided to consumers to assist them in the complaints process.

Recommendation 14: A “reasonableness” test should be applied by the AP to determine if it is reasonable to refuse a consumer request.

Recommendation 15: Service provision should be guided by outcomes, rather than specific in/exclusions. These outcomes should be reflective of CDC principles.

Recommendation 16: At all package levels, funds should be able to be utilised to provide or purchase nursing, allied health or other specialist services as well as assistive technology, aids or equipment.

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Conclusion

This paper provides advice to the Government on the policy underpinnings of the new CDC Home Care Packages. It is also designed to assist in the development of the Program Guidelines and other information products. The paper represents formal Alliance advice at this point in time and may be updated as the development and implementation of the CDC Home Care Packages continues to evolve.

The National Aged Care Alliance is the representative body of peak national organisations in aged care including consumer groups, providers, unions and professionals.



Please note the following member of the Alliance has abstained from endorsing this document:

