SUBMISSION ON THE DRAFT *HOME CARE PACKAGES PROGRAM GUIDELINES*

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About NCOSS

The Council of Social Service of NSW (NCOSS) is the peak body for the community and human service sector in New South Wales. We advocate for effective public policy that reduces inequality and disadvantage in NSW.

NCOSS provides independent and informed policy development, advice and review and plays a key coordination and leadership role for the non-government, not-for-profit social and community services sector in NSW. NCOSS works with our members, the community sector, government and other relevant agencies on social, systemic and operational issues.

NCOSS membership is composed of community organisations and interested individuals. Affiliate members include local government councils, business organisations and Government agencies. Member organisations are diverse, including unfunded self-help groups, children's services, youth services, disability service providers, emergency relief agencies, community care service providers, family support agencies, housing and homeless services, mental health, alcohol and other drug organisations, Aboriginal community organisations, faith-based groups, peak organisations and a range of consumer advocacy agencies.

Summary of Recommendations

1. That consultation in relation to the *Living Longer. Living Better.* reform package is aligned to the Shared Principles in the National Compact.

2. That the evaluation of the Home Care Packages program assesses how well the program supports the realisation of the human rights of consumers.

3. That DoHA pilots an entitlement based approach, as proposed by the Productivity Commission, in selected locations around Australia.

4. That DoHA commissions a study of the true costs of community aged care services to inform the evaluation of the Home Care Packages program.

5. That the evaluation of the Home Care Packages program assesses the effectiveness of the system of pre-defined levels of Home Care Packages for meeting the degree and nature of need in the community.

6. That upholding and realising human rights is included as an objective of the program.

7. That people with lifelong or long-term disability are included as a Special Needs Group in the Home Care Packages program.

8. That DoHA develops a strategy to provide appropriate support for older people with disability who cannot access appropriate disability supports through DisabilityCare Australia.

9. That the evaluation of the Home Care Packages program assesses the performance of the CDC implementation in the Home Care Packages program against international best practice for responsiveness, person centredness, flexibility and choice.

10. That the evaluation of the Home Care Packages program assesses the impact of sub-contracting and brokerage charges on consumers.

11. That DoHA develops a revised planning and allocation framework that allows for direct allocations of Home Care Packages to consumers.

12. That arrangements for transferring aged care places between providers are revised and simplified.

13. That any Home Care Package allocated before the 2012-13 Aged Care Approvals Round is converted into a CDC package if it becomes vacant after 1 July 2013.

14. That the evaluation of Home Care Packages includes performance measures to the skill and responsiveness of providers at supporting consumer decision-making, and at finding creative solutions for consumers with complex needs.

15. That the Australian Government invests in capacity building initiatives for the community aged care sector to improve the capability of the sector to implement CDC.

16. That the CDC principles are amended to include:
    - support for consumer decision-making,
    - responsiveness to culture, family and relationships,
    - social inclusion, and
    - Closing the Gap in Aboriginal and Torres Strait Islander health and wellbeing.

17. That the evaluation of the Home Care Packages program assesses the performance of the program against the Program Objectives and CDC Principles.

18. That realisation of human rights is defined as a core principle of the program.

19. That wellness/re-ablement is elevated to become a general principle for the Home Care Packages Program.

20. That the principle of wellness and re-ablement in the Guidelines is re-worded to state: *Home Care Packages should be delivered within a restorative or re-ablement framework that aims to optimise the functional capacity of the consumer according to their personal goals. Re-ablement should enable each consumer to explore individual strengths and goals, and work towards achieving the outcomes they desire. Services offered in a framework that emphasises wellness should be responsive to the cultural, personal, family and individual circumstances and relationships in the consumer's life.*

21. That the evaluation of the Home Care Packages program is independent of DoHA.

22. That the evaluation of the Home Care Packages program includes evaluation of all new arrangements, including new fee and subsidy structures, processes for ACAT approval, and waiting list management.

23. That the evaluation of the program includes an assessment of:
    - the impact of broad banding of assessments on prioritisation;
    - the capacity of providers to undertake decision support;
    - specific attention on impact of CDC on Aboriginal and Torres Strait Islander and culturally and linguistically diverse consumers, and their families and carers;
    - the impact of brokerage/sub-contracting;
    - whether the Home Care Standards reflect the objectives and aims of the program;
    - if it is retained, the impact on CDC of the specified list of services; and
    - interface issues with other programs.

24. That any assessment process for Home Care Packages involves face to face assessment, preferably in the person's home.
25. That Home Care Packages offering re-ablement interventions can be delivered on a short term basis.

26. That the draft Guidelines are amended to state that ACATs should always offer information about the variety of options available to the consumer.

27. That the evaluation of the program assesses the clinical and financial impact for people who receive a lower package than they are assessed as needing.

28. That ACATs must be involved in prioritisation and waiting list management for Home Care Packages.

29. That ACATs are specifically resourced to undertake waiting list management.

30. That a language and cultural supplement is introduced and made available to Aboriginal and Torres Strait Islander consumers and consumers from culturally and linguistically diverse communities to assist with any language or cultural interpretation and support that people from these communities may need.

31. That the Charter of *Rights and Responsibilities for Home Care* is included as part of every Home Care Agreement.

32. That the consumer's rights with respect to transparency of the budget should also be recorded in the Agreement. This includes rights with respect to unspent funds and any planned contingency.

33. That sub-section 3.1.3 'Level of consumer control over the management of the package' in Part D, is deleted from the Guidelines and replaced with a discussion of supported decision-making.

34. That the Guidelines specify that the budget for a Home Care Package must reflect the level of management and administration being undertaken by the consumer.

35. That sub-section 3.1.4 is deleted from the Guidelines.

36. That sub-section 3.1.5 'Case management' in Part D is broadened with best practice examples of case management from a person centred approach.

37. That sub-section 3.1.8 in Part D refer to the rights of the consumer to take risks, and discuss the concept of dignity of risk.

38. That the evaluation of the Home Care Packages program assesses the impact of sub-contracting on costs, and the impact on the quality and quantity of services available to consumers.

39. That the word "informal" is deleted from the Guidelines when used in reference to carers, in accordance with the *Carer Recognition Act 2010*.

40. That the provision to fund advocacy from a Home Care Package as an administrative cost is deleted from the Guidelines.

41. That the definition of a contingency includes only a planned contingency, and not planned savings for later expenditure, or unplanned savings. Consumers should be able to retain any savings in addition to the planned contingency.

42. That providers are required to transfer unspent funds to any new package when a consumer leaves a Home Care Package.
43. That sub-sections 2.1.3 and 2.2.3 of Part E apply only to non-CDC packages.

44. That illustrative examples of innovative and creative use of a package are included in the Guidelines.

45. That the provision for a Home Care Package to fund advocacy is deleted from the Guidelines, as advocacy is available to all consumers of Commonwealth aged care programs through the National Aged Care Advocacy Program.

46. That the definition of 'emotional support' in the Guidelines is updated to reflect a positive view of ageing, caring relationships, and in accordance with wellness and re-ablement approaches.

47. That any services or items that can be demonstrated to support a person to achieve goals as stated in their care plan are not excluded from a Home Care Package.

48. That payments for assistance with accommodation costs, travel, entertainment, food, customised aids and motorised wheelchairs are deleted from the list of excluded services and items.

49. That providers are required to maintain continuity of support where a consumer moves locality for a short term or fixed duration.

50. That financial hardship is not a reason to be denied security of tenure in a Home Care Package.

51. That any consumer on leave from a package for more than 7 days should be charged a reduced fee, or the basic daily fee should be suspended during the period of leave.

52. That the *Charter of Rights and Responsibilities for Community Care* is amended as follows:
    - Section 1. a) currently states "to be treated and accepted as an individual, and to have my individual preferences respected."
      This should be amended to state "to be treated and accepted as an individual, and to have my individual preferences supported."

    - Section 2. a) currently states "to be involved in identifying the community care most appropriate for my needs."
      This should be amended to state "to identify goals for myself and use my Home Care Package to achieve those goals."

    - Section 2. b) currently states "to choose the care and services that best meet my assessed needs, from the community care able to be provided and within the limits of the resources available."
      This should be amended to state "to make choices about how, why, when, where and by whom support is provided to meet my assessed needs and achieve my identified goals, within the resources available."

53. That DoHA specifically consult NACAP funded organisations across Australia about the draft Guidelines before they are finalised.

54. That the Aged Care Complaints Scheme is reviewed for its capacity to respond to Consumer Directed Care.

55. That DoHA undertakes modelling of more progressive fee structures which would have a lesser financial impact on low income part-pensioners.

56. That a formal diagnosis is not required for a person to access the dementia supplement to their Home Care Package.

57. That the oxygen supplement is reviewed for its compatibility with a CDC approach.

58. That any determinations of financial hardship by the Secretary must take into account housing, health care, utility, and family related expenses.

59. That the Guidelines are amended to note that consumers of Home Care Packages may access HACC funded clinical services in addition to a Home Care Package.

60. That Home Care Package consumers may use package funds to pay costs of accessing Day Therapy Centre services.

61. That DoHA and DVA monitor the use of DVA programs by Home Care Package consumers and that the evaluation of the Home Care Packages program assesses whether the interface arrangements should continue.

Introduction

NCOSS welcomes the opportunity to comment on the draft *Home Care Packages Program Guidelines* (the Guidelines). These draft Guidelines offer an important opportunity for policy and program development in aged care in Australia. They introduce Consumer Directed Care (CDC) into the mainstream of aged care policy. It will therefore be vital that these Guidelines are consulted upon broadly and subject to wide scrutiny.

NCOSS has a range of regular consultative mechanisms through which we provide responses on government policy development and program initiatives. In preparing this response to the draft Guidelines NCOSS consulted with members of the NSW HACC Issues Forum, the NSW Aged Care Alliance, and the NSW HACC Development Officers Network. Due to the very short time frame for providing a response, NCOSS was not able to canvass all the relevant stakeholders, particularly members from regional and remote areas, Aboriginal and Torres Strait Islander representatives, and stakeholders working with culturally and linguistically diverse communities.

NCOSS is deeply concerned that a number of important stakeholders have not been able to provide feedback. NCOSS is aware of many individuals and organisations who would have provided feedback had the Department of Health and Ageing provided a longer time frame for a response.

It would be preferable for all further consultation to be conducted in accordance with the Shared Principles in the National Compact with the not-for-profit sector, which state:

- *We aspire to a relationship between the Government and the sector based on mutual respect and trust.*
- *We agree that authentic consultation, constructive advocacy and genuine collaboration between the sector and the Government will lead to better policies, programs and services for our communities.*[1]

Recommendation

1. That consultation in relation to the *Living Longer. Living Better.* reform package is aligned to the Shared Principles in the National Compact.

[1] Australian Government (2012) *National Compact: working together*, Canberra.

A person centred approach

These Guidelines are an important step in reforms to aged care. The Guidelines will form the policy framework within which aged care services become responsive to frail older people's needs and goals. The Consumer Directed Care (CDC) initiative is an important step towards achieving this outcome.

However, NCOSS considers that the concept of a **person centred approach**, particularly as it is conceptualised in the disability sector, better captures the aims and outcomes that are important to people who use funded services to meet their support needs. Attempts to personalise support services through approaches like CDC must be seen in the broader context of the very *purpose* of providing support services.

The purpose of a person centred approach in disability support is to enable a person to achieve their life goals. Exercising choice and control in life is often unavailable to people as a result of needing support with daily activities. Exercising autonomy over what, how, why, and by whom support is delivered is important to full participation in community life, and realisation of personal humanity. Person centred approaches to support therefore go beyond conceiving of people using funded support as consumers who are exercising marketplace choice. Person centred approaches contextualise those choices in what is meaningful to the person. Exercising autonomy is central to realising those meaningful objectives.

In this respect, the disability sector in Australia has been successful in using the United Nations Convention on the Rights of Persons with Disabilities[2] to re-frame how support is conceived and delivered for people with disability around realisation of human rights. More than the rights of consumers of services to exercise choice in how those services are delivered, a person centred approach aims towards realisation of human rights in the provision of support. This goes beyond the definition of CDC in the draft Guidelines as "a way of delivering services that allows consumers to have greater control over their own lives by allowing them to make choices about the types of care they access and the delivery of those services, including who will deliver the services and when" (p. 8).

NCOSS supports CDC initiatives, as they can form a component of a person centred approach. However, without a policy framework that recognises and supports the autonomy of people using funded support as a fundamental component in their overall wellbeing, CDC may not be very person centred in its implementation.

These conceptual issues have a number of specific and concrete implications for the delivery of CDC initiatives, which this submission will detail in relation to the draft Guidelines.

Recommendation

2. That the evaluation of the Home Care Packages program assesses how well the program supports the realisation of the human rights of consumers.

[2] United Nations (2006) *Convention on the Rights of Persons with Disabilities*, New York.

Part A

2. A New Home Care Packages Program

2.1 Package Levels

The four pre-defined levels of Home Care Packages, along with supplements, offer more scope for responsiveness to people's identified needs. Along with new supplements to the package, package resources will be able to more effectively address frail older people's needs.

For support to be person centred, it must be responsive to a person's needs and aspirations at the time a person has those needs and aspirations. A person centred approach to support arrangements would tend to minimise unnecessary external requirements and systems, so the person can obtain the maximum benefit from flexible supports.

The introduction of Levels 1 and 3 into the Home Care Package Program still falls short of this outcome. The entitlement to support that the Productivity Commission proposed in its report, *Caring for Older Australians*[3], offers much greater scope for achieving a person centred outcome. An entitlement model would offer:

- greater personal **control and choice** over supports,
- **portability** of support,
- **flexibility** in allocating resources in a way that is responsive to needs,
- ensuring **seamless access** and progress through aged care services,
- **continuity** of services as a person's needs change, and
- **timeliness** of delivering support.

The rationale for the designated levels of Home Care Packages is not clear. Without a strong basis of evidence to justify each of the specified levels, it is difficult to determine if they are in fact responsive to need in the community. Retaining pre-defined levels within Home Care Packages would tend to compromise continuity and timeliness of supports, as it is likely that a person would have to move to a new provider to move between the levels.

The entitlement model proposed by the Productivity Commission also allows for portability of supports, which would enhance timeliness and responsiveness to changes in need. A frail older person is likely to need to relocate because of the nature of their support needs escalating to a level such that they can no longer live alone. Ensuring that people are supported in these transitions will support the overall objectives of the program and the Government's policy objectives of supporting people to remain out of residential care for longer.

The amendments to the *Aged Care Act 1997* proposed in the *Aged Care (Living Longer Living Better) Bill 2013* offer scope for the review of the Act to consider the entitlement model proposed by the Productivity Commission. While NCOSS supports this consideration, NCOSS is concerned that this will further delay the implementation of a more effective program of supports for older people living in the community. Evidence from the implementation of the Home Care Packages Program will necessarily be required to assess the prospects for a different model for the program. NCOSS therefore proposes that the Department of Health and Ageing (DoHA) chooses defined locations to pilot the entitlement approach, in order to assess the effectiveness of the Home Care Packages program against the proposed Productivity Commission model.

[3] Productivity Commission (2011) *Caring for Older Australians*, Report No. 53, Final Inquiry Report, Canberra, pp.155-174.

NCOSS also supports the call for an independent study of the costs of aged care services, which can inform any further determinations about the levels of Home Care Packages and unit pricing for services. NCOSS is particularly concerned to determine the true cost of service delivery to people with special needs and people living in remote, regional and rural areas to ensure that appropriate resources can be allocated to people with special needs.[4]

The evaluation of the Home Care Packages program will also need to gather evidence about the effectiveness of the package levels for meeting the needs of the community, and in particular, whether they are appropriate for the degree of need of frail older people in the community.

Recommendations

3. That DoHA pilots an entitlement based approach, as proposed by the Productivity Commission, in selected locations around Australia.
4. That DoHA commissions a study of the true costs of community aged care services to inform the evaluation of the Home Care Packages program.
5. That the evaluation of the Home Care Packages program assesses the effectiveness of the system of pre-defined levels of Home Care Packages for meeting the degree and nature of need in the community.

2.2 Program Objectives

NCOSS supports the currently defined program objectives, and would also recommend that the program also aims to deliver quality services. Lack of any mention of quality in these Guidelines outside of the discussion of rights and responsibilities gives the impression that only providers are responsible to government for ensuring quality in supports delivered under the program. All parties have a responsibility for ensuring high quality services.

While NCOSS appreciates that these objectives are relevant to both CDC and non-CDC packages, the objectives of the program will also need to change as existing Home Care Packages are converted into CDC packages. More specific program objectives, possibly incorporating principles relating to CDC, would be more appropriate to the program as a whole after this time.

In the intervening period, NCOSS recommends that upholding and realising human rights is included as an objective of the program.

Recommendations

6. That upholding and realising human rights is included as an objective of the program.

[4] For instance, the roundtable proceedings on *Better Indigenous Policies* held by the Productivity Commission in 2012 identified that service delivery to Aboriginal and Torres Strait Islander people can involve increased cost (p. 25).
See Fitzgerald, R. (2012) ‘Chapter 2: Outcomes for Indigenous Australians — the current situation’ in *Better Indigenous Policies: The Role of Evaluation – Roundtable Proceedings*, Productivity Commission, Canberra.

2.4 Special Needs Groups

NCOSS recommends that people with lifelong or long-term disability are considered as a group who has special needs. This would be consistent with the inclusion of care leavers[5], veterans, people who are homeless or at risk of being homeless, and lesbian, gay, bisexual, transgender and intersex persons in the relevant section of the Act.

People with lifelong or long-term disability over the age of 65, and people who acquire non-ageing-related disability after the age of 65, have recently come to public attention through discussion in relation to the National Disability Insurance Scheme (NDIS, now called DisabilityCare Australia). The provisions for the Scheme cover only people who make an access request to the NDIS before they turn 65 years of age. This will mean that there are significant numbers of people with long-term or lifelong disability who will not have access to the NDIS, and who will instead need to rely on aged care services. People who acquire a disability after they turn 65 will be in similar circumstances.

Aged care services have historically not been able to support people with non-ageing-related disabilities appropriately, nor are they funded to do so. Pricing for residential aged care, Community Aged Care Packages (CACPs) and Extended Aged Care at Home (EACH) packages do not take into account needs arising from a person's disability. Workers in aged care services are also not usually trained to work with people with non-ageing-related disability.

People using disability services aged over 65 will be subject to the terms of the *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*[6], which specifies that the Commonwealth (Department of Health and Ageing) is responsible for funding their supports. It's not clear what will happen for these people once the NDIS comes into effect – if the services they are using will need to continue as they are, even while younger people using the same service but accessing the NDIS might change their support arrangements. It is possible that some specialist disability services may not continue, or will change significantly because service providers will have increased flexibility to respond to demand. In these circumstances, where funding and support options for people with disability who are over 65 also does not change, it is likely they will enter residential aged care. This may be an inappropriate environment for them and more costly than alternatives.

NCOSS therefore recommends that the Australian Government develop a strategy to ensure that people with lifelong or long-term, non-ageing-related disability have their support needs met appropriately, and that the aged care system is responsive to their specific needs. For people using specialist disability services who are over 65, NCOSS recommends that people in these circumstances are resourced by DoHA to access the NDIS.

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[5] The current *Community Packaged Care Guidelines* define care leavers as "Forgotten Australians, former child migrants and people from the Stolen Generations. Many care-leavers prefer to be called Forgotten Australians as they do not identify as being receivers of 'care' from the institutions they spent time in as children. Forgotten Australians is considered the term least likely to offend." (p. 70). The *Allocation Principles 1997* section 4.4D specifies that care leavers are considered as people with special needs.

[6] Council of Australian Governments (2008) *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*, Canberra, available at: http://www.federalfinancialrelations.gov.au/content/npa/health_reform/transitioning_responsibilities/national_partnership.pdf (last accessed: 16 May 2013).

Recommendations

7. That people with lifelong or long-term disability are included as a Special Needs Group in the Home Care Packages program.
8. That DoHA develops a strategy to provide appropriate support for older people with disability who cannot access appropriate disability supports through DisabilityCare Australia.

3. Consumer Directed Care

3.1 What does CDC mean in the context of Home Care Packages?

The variety of models of CDC around the world offers Australia a number of opportunities to learn from superior practice in policy development and implementation.

> *There is no single model of consumer directed care, and CDC rarely stands alone but is commonly one component of a wider service program. Conceptually, CDC is most positively defined as a means of enhancing client autonomy by giving the client control over the care they are to receive from paid providers, including paid family members. It thus represents the opposite of agency directed care which is controlled by the service provider. The scope of consumer direction as practiced in different programs varies widely.*
>
> *At its narrowest, CDC means that the client, and their carers where present, have a greater say in the planning of care to be provided by agencies and in the delivery of services than is usually the case.*[7]

In accordance with a person centred approach, as discussed above, NCOSS supports implementation of the fullest extent of consumer direction in the Home Care Packages program. NCOSS recommends that the evaluation of the Home Care Packages program assesses the performance of the CDC implementation in the Home Care Packages program against international best practice for responsiveness, person centredness, flexibility and choice.

However, there are a number of elements of the program as outlined in the draft Guidelines which narrow the scope of consumer direction and re-assert a provider-centred system. Some of these elements conflict with some providers' existing practice in this area, indicating that the Australian Government's policy settings are more limited.

As the reform process extends over a number of years, there is scope for the Australian Government to trial alternative approaches, particularly the entitlement model proposed by the Productivity Commission.

NCOSS considers the management and delivery of the package by a single provider to be a conflict of interest and in tension with a person centred approach. Where packages are allocated to providers, consumers are a third party to a contract that is primarily between government and a non-government organisation. A person centred approach aims to reverse this relationship, and ensure that services are accountable to consumers. The Productivity Commission's proposed entitlement model would deliver such a shift, and make certain levels of regulation, such as detailed planning controls, process-focused quality standards and output-based reporting, unnecessary. Without such a shift, NCOSS recommends rigorous requirements and evaluation of providers' implementation of CDC to ensure consumers can exercise autonomy and obtain the highest standard of support.

[7] Howe, A. (2003) *Is Consumer Directed Care a direction for Australia?*, paper prepared for Alzheimer's Australia, Melbourne.

The evaluation of the CDC pilots reported that:

> *CDC providers have an incentive to encourage clients to use their own in-house services, and some CDC providers have an internal organisational policy to increase their in-house services and decrease their use of brokered services.*
>
> *For many participants, the decision to use the provider's in-house services was based on price, as the cost of brokered services was often higher, particularly in areas where there was limited choice and if the CDC provider charged an additional fee for arranging brokered services.*[8]

In these cases, providers were reducing the overall services available to the person, by charging an additional fee, as a result of the person exercising their right to choose alternative service providers. NCOSS is extremely concerned at the constraints that will inherently be placed on choice for consumers because providers have an incentive to reduce the level of choice available. Under these arrangements, appraisals about the nature and scope of choice and control exercised by consumers are necessarily limited.

Recommendations

9. That the evaluation of the Home Care Packages program assesses the performance of the CDC implementation in the Home Care Packages program against international best practice for responsiveness, person centredness, flexibility and choice.
10. That the evaluation of the Home Care Packages program assesses the impact of sub-contracting and brokerage charges on consumers.

Planning and the Aged Care Approvals Round

Allocation of packages through the Aged Care Approvals Round will be maintained, and DoHA has not indicated that there will be any change to this process. NCOSS is disappointed at this missed opportunity to transform the allocation process to align with a person centred approach.

An entitlement model would do away with the need for a planning process limited by data validity (particularly where data are out dated, or where statistical significance is difficult to establish), and by those providers who are approved providers under the *Aged Care Act 1997*, and who apply for new places.

As discussed above, allocation of resources to providers, rather than consumers, reiterates a provider-centric approach and undermines the scope for a person centred approach. Even without an entitlement model, a more systematic process for allocating support resources to people in need may be pursued as the implementation of the Aged Care Gateway/national contact centre progresses. Such a process would be able to target support to people in significant need, and ensure that people in disadvantaged population groups, such as Aboriginal and Torres Strait Islander people and people at risk of homelessness, could be targeted more directly for support.

NCOSS recommends that the evaluation of the Home Care Packages program also evaluates the extent to which the Aged Care Approvals Round process supports or hinders the implementation of CDC, and options to transform the planning and allocation process to a more person centred model.

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[8] KPMG (2012) *Evaluation of the consumer-directed care initiative – Final Report*, KPMG for the Department of Health and Ageing, Canberra, January, pp. 48-49.

In the interim, provisions for transfer of places between providers in the *Aged Care Act 1997* may be made simpler to facilitate continuity of support for consumers.

NCOSS also recommends that any vacant package allocated before the 2012-13 Aged Care Approvals Round is converted to a CDC package after 1 July 2014. Consumers accepting a Home Care Package after 1 July 2014 will be subject to new arrangements under the *Aged Care Act* for fees and subsidies. In these circumstances, where consumers are likely to be paying higher fees than for packages allocated earlier, it is appropriate that consumers have access to the full range and extent of choice available to other consumers.

Recommendations

11. That DoHA develops a revised planning and allocation framework that allows for direct allocations of Home Care Packages to consumers.
12. That arrangements for transferring aged care places between providers are revised and simplified.
13. That any Home Care Package allocated before the 2012-13 Aged Care Approvals Round is converted into a CDC package if it becomes vacant after 1 July 2013.

Sector capacity and best practice in implementing CDC

The community aged care sector is quite varied in implementing CDC in practice. NCOSS is concerned that the variability of practice in this area for the prospects of ensuring that all consumers have choice and control in the services they use. Providers that participated in the CDC pilots from 2010-11 have had considerable experience with CDC, some having made substantial innovations in service delivery in order to implement CDC. Other service providers will have had very little experience with CDC and will need to make extensive changes in operations in order to successfully implement CDC to the fullest extent, towards a person centred approach. Substantial variation was identified even among providers participating in the CDC pilot.[9]

NCOSS suggests that the level of administrative control exercised by consumers may be a reflection of the level of support for consumer choice and control by providers. As discussed above, where organisational policy conflicts with or limits consumer choice, organisational policy has held sway. Conclusions about the extent of choice and control consumers are willing and able to exercise must be seen in the context of the broader institutional and structural requirements for supporting CDC, and where they do not support CDC principles.

The skill, responsiveness and creativity exercised in designing and delivering support can be measured. NCOSS strongly recommends that evaluation of the Home Care Packages Program includes performance measures relating to the skill and responsiveness of providers at supporting consumer decision-making, and at finding creative solutions for consumers with complex needs.

NCOSS recommends that DoHA resources capacity building initiatives to support providers to implement CDC and to transition to a person centred approach. For some providers, considerable assistance will be needed with conceptual and practice issues. For others, technical and administrative changes associated with implementing individual budgets will be needed. All of these types of change have associated costs, which at the moment are borne by providers. NCOSS recommends that capacity building and transition resourcing initiatives particularly target providers who work with vulnerable and disadvantaged

[9] KPMG (2012) Ibid.

populations where there may be social, economic and/or cultural barriers to participating in CDC.

Recommendations

14. That the evaluation of Home Care Packages includes performance measures to the skill and responsiveness of providers at supporting consumer decision-making, and at finding creative solutions for consumers with complex needs.
15. That the Australian Government invests in capacity building initiatives for the community aged care sector to improve the capability of the sector to implement CDC.

3.2 CDC Principles

NCOSS supports the potential of Consumer Directed Care (CDC) to deliver a person centred approach to supporting frail older people. The principles outlined in the draft Guidelines offer a useful framework to build upon. NCOSS suggests that the evaluation of the program must assess its effectiveness according to these principles. Defining the principles and specifying what is comprised in those definitions will also be useful for providers to deliver a CDC approach. NCOSS therefore suggests the additions and amendments below to the principles outlined in the draft Guidelines.

Supporting consumer decision-making

Making decisions about how, why, when, where and by whom support is provided is not only important to ensuring consumer choice and satisfaction with services. It is also important to the realisation of human rights and to full and active participation in society. Supporting decision-making in Home Care Packages takes place at all levels, from initial contact, through the assessment process, to case management or co-ordination. All parts of the aged care system must focus on supporting consumer decision-making.

> *Central to the successful implementation of consumer directed care and advance care planning is the consideration that is given to the freedom and right of a person to actively participate in decision-making about their health care and personal matters and to have those decisions respected… Recognition of capacity is fundamental to human personhood and the freedom to make decisions regarding one's own health.*[10]

An important aspect of consumer choice and control (principle 3.2.1) is the practice of supported decision-making. For people with dementia or mental health conditions which may affect their decision-making capacity, it is important that the CDC policy framework supports their right to exercise choice and to be supported in doing so. In a legal sense, determinations of capacity are specific to the context and the decision under consideration, and a person's decision-making capacity may change over time. Where people do not have capacity to make a particular decision, the legal arrangements for ensuring that their rights and interests are protected should be respected.

In a more general sense, supporting consumer decision-making will be critical to the implementation of CDC. This goes beyond control over administrative elements of the package, to the exercise of autonomy in designing and delivering support. A consumer may require a large amount of support to make decisions and manage the package, but nevertheless have exercised a great deal of autonomy; conversely, a consumer may be

[10] Australian Human Rights Commission (2012) *Respect and choice: A human rights approach for ageing and health*, Sydney, p. 16.

managing significant parts of the package but have had few options about the purpose or nature of the supports.

Consumers often do not know or understand what options they may have, and most would not have had experience with care planning and decision-making about support services. Understanding a person's goals and aspirations, and the ability to explore possibilities for the person, in the context of frailty and/or disability requires skill and creativity. Current approaches in case management often do not emphasise this kind of approach, particularly where a provider may have been operating in more of a menu-driven service environment. Explicating principles regarding supporting consumer choice can guide providers, while also providing useful standards against which to evaluate CDC implementation across the sector.

Many of the following principles of supported decision-making would be useful to apply in general in implementing CDC:

- *People are capable of making decisions about most areas of their lives.*
- *Everyone has a will and can communicate their will and preferences. These preferences can be built into valid decisions.*
- *The person should receive whatever support they need and wish to receive in order to make decisions.*
- *Competency can be learned, influenced, enhanced and suppressed.*
- *The person makes and retains control over the decisions made and takes responsibility for them.*
- *People have the right to take risks in their lives.*
- *People do not always make good decisions but can learn from their mistakes and experience.*
- *Supported decision-making must involve the full agreement of the person and his/her supporters.*
- *Support should be independent of service delivery.*[11]

Section 3.1.4 of the draft Guidelines refers to substitute decision-makers who may have authority to make a decision. However, support for those who have limited capacity is not discussed in the Guidelines. NCOSS suggests increasing the discussion about supported decision-making and decision support.

To make robust and well-informed decisions about supports, consumers need to have:

- a clear understanding of what is possible,
- support co-ordinators and case managers who are able to work flexibly and creatively, and
- options to change their support arrangements if they wish to.

Responsiveness to culture, family and relationships

NCOSS suggests that DoHA adds an additional principle of cultural responsiveness to the principles for CDC. While cultural responsiveness is not excluded in how CDC is implemented, the Home Care Packages Program must be responsive to the entirety of the target population. NCOSS has heard concerns from some stakeholders that people from

[11] Office of the Public Advocate Victoria (2009) *Supported decision-making: Background and discussion paper*, Melbourne, p. 9.

Aboriginal and/or Torres Strait Islander and culturally and linguistically diverse communities may have significant issues with the decision making framework for CDC in these Guidelines.

In many Aboriginal and/or Torres Strait Islander, and culturally and linguistically diverse communities, caring for frail older relatives is the responsibility of particular family members. Decision-making about support must recognise the relationships within the consumer's life and the existing interdependencies of a family or community. This process must ensure the cultural safety[12] of Aboriginal and Torres Strait Islander and culturally and linguistically diverse consumers, workers, and their families and communities.

While there may be specific cultural obligations for caring in Aboriginal and/or Torres Strait Islander, and culturally and linguistically diverse communities, each family situation involves unique relationships. Respecting carers and other important people in the life of the consumer will be crucial to ensuring the success of services.

Social Inclusion and Closing the Gap

For many people their social and economic circumstances will have had a life-long effect on their health. Frail older people, particularly those who have experienced social disadvantage throughout their lives, tend to have complex health conditions and support needs as a result of a lifetime of cumulative disadvantage. Factors such as income, housing and education all contribute to adverse wellbeing in later life.

A CDC approach has considerably more scope to support social inclusion than community care focused on particular service types or interventions. In combination with a wellness model, CDC offers the opportunity to address the variety of disadvantages over people's lifetimes that may contribute to adverse health and psycho-social outcomes.

While a care plan under these draft Guidelines has scope to address a variety of the identified goals of the person, goals relating to a person's disadvantaged circumstances, or which would be affected by those circumstances, must also be recognised.

NCOSS supports the Close the Gap campaign to improve Aboriginal and Torres Strait Islander health in Australia. In order to Close the Gap, holistic actions to improve the health and wellbeing of Aboriginal and Torres Strait Islander people need to be taken from a variety of agencies working in concert. Recognition of aged care service providers' role and responsibilities in this process is an important step to ensuring that Aboriginal and Torres Strait Islander people can attain a higher standard of health.

NCOSS suggests including social inclusion in the core principles of the CDC Home Care Packages program to ensure that action on social factors that contribute to poor health and wellbeing is supported at all levels of the program.

3.2.2 Rights

As discussed above, NCOSS supports a person centred approach to support, in which realisation of human rights is central to the overall purpose of support. In this perspective, a person does not only have a right, based on assessed need, to the services that will assist them. They also have a right to the highest attainable standard of health, to full participation in the community, to an adequate standard of living, and, for Indigenous people, to practice cultural traditions. Supports and services must assist people to realise these rights through the exercise of choice and control over those supports. NCOSS recommends that this

[12] NACCHO (2011) *Creating the NACCHO Cultural Safety Training Standards and Assessment Process: A background paper*, National Aboriginal Community Controlled Health Organisation, Canberra.

section is amended to state that realisation of human rights is a core principle of the program.

NCOSS also recognises that people using Home Care Packages have specific rights, such as the right to participate in decision-making, and rights to services that are safe and of an appropriate standard of quality. These rights must be enumerated in the core principles of the program. NCOSS recommends that this section is amended to specify that older people using Home Care Packages have specific rights, such as those enumerated in the *Charter of Rights and Responsibilities for Community Care*.

Recommendations

16. That the CDC principles are amended to include:
    - support for consumer decision-making,
    - responsiveness to culture, family and relationships,
    - social inclusion, and
    - Closing the Gap in Aboriginal and Torres Strait Islander health and wellbeing.
17. That the evaluation of the Home Care Packages program assesses the performance of the program against the Program Objectives and CDC Principles.
18. That realisation of human rights is defined as a core principle of the program.

3.2.5 Wellness and Re-ablement

NCOSS has had a considerable history of supporting wellness and re-ablement in community care. In NSW, the preferred term for these approaches is Enablement, or the Enabling Approach. The NSW Department of Family and Community Services division of Ageing, Disability and Home Care (ADHC) defines an Enabling Approach as:

> *an umbrella term which includes evidence–based practices associated with wellness, active ageing, early intervention, person-centred responses, preventative intervention and short term restorative or 'reablement' interventions. This approach aims for increased functionality in performing the common tasks of daily living and improved feelings of personal wellbeing.*[13]

From late 2008 NCOSS participated in the IMPACT Working Group in NSW, a collaboration of industry peak organisations, consumer organisations, providers and government, which advocated implementing Enabling Approaches into Home and Community Care (HACC) services in NSW. The IMPACT Working Group developed the following principles for an Enabling Approach:

1. Person-centred & enables each consumer to explore individual strengths & goals & work towards achieving the outcomes they desire, with security of support for those who need it.
2. Culturally-appropriate, socially inclusive, & sensitive to individual circumstances, social context & relationships, enabling the consumer to continue with what is important to them.
3. Flexible & responsive to the range of changing needs, interests & choice of consumers.
4. Supportive & enables the positive relationship between consumers & carers.
5. Recognised as a fundamental & valued part of society that grows & develops to meet the changing expectations of consumers, carers, funders & the workforce.

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[13] ADHC (2012) *Better Practice demonstration projects evaluation*, Sydney, October, p. 3.

The Enabling Approach in NSW has thus had a much broader focus than the definition of wellness and re-ablement presented in the principles for CDC. NCOSS is concerned that the definition has a number of limitations in its implementation. The broader definition and principle of Enablement as outlined above, on the other hand, has a broader application.

NCOSS is concerned that the definition of re-ablement in this section of the draft Guidelines is overly prescriptive, is clinical without being clinically justified, not culturally responsive, and does not capture the breadth of practice being undertaken under the umbrella of re-ablement, wellness, Active Service, and related approaches. Furthermore, NCOSS is concerned that the draft Guidelines define the primary focus of the Home Care Packages program as "potentially reducing the need for ongoing and/or higher levels of service delivery". NCOSS opposes the introduction of re-ablement purely to reduce costs. Rather, re-ablement must relate to the wellbeing of the person as defined by them on their own terms.

NCOSS cautions against defining wellness and re-ablement purely in terms of independence. For many cultures, family obligations require people to assist older family members, and absolute independence is not the highest priority in older age, nor is it functionally possible. However, maintaining functional capacity, and/or re-learning activities in new ways to allow for the effect of frailty or disability, are important objectives. These objectives are important in the overall context of a person's life. Maintaining strength and flexibility are important to be able to undertake certain tasks, which are meaningful to the person. A wellness/re-ablement approach should always implement interventions in the context of the person's overall plan and their personal goals.

NCOSS is also concerned at the directive in the draft Guidelines that "there should always be an assumption that the older person can regain their previous level of function" (pp. 9-10). While this is an admirable aspiration, in reality it is not always clinically warranted. A person who has a stroke or injury may not ever be able to regain the functional capacities they had prior to the health episode. However, optimising the person's function after illness or injury is often possible, at times requiring skill and creativity from the service provider and the consumer. NCOSS therefore recommends redefining this principle.

A CDC framework is not essential to implement re-abling interventions. All Home Care Packages should have the benefit of offering re-abling interventions where these are identified as important to the consumer. NCOSS recommends that wellness and re-ablement is re-aligned to become a general principle for all Home Care Packages, not only those offered on a CDC basis.

Recommendations

19. That wellness/re-ablement is elevated to become a general principle for the Home Care Packages Program.
20. That the principle of wellness and re-ablement in the Guidelines is re-worded to state:
    Home Care Packages should be delivered within a restorative or re-ablement framework that aims to optimise the functional capacity of the consumer according to their personal goals. Re-ablement should enable each consumer to explore individual strengths and goals, and work towards achieving the outcomes they desire. Services offered in a framework that emphasises wellness should be responsive to the cultural, personal, family and individual circumstances and relationships in the consumer's life.

Evaluation

It is not clear from the description of the evaluation of the Home Care Packages program in Part A, section 5 whether the evaluation will consider only matters relating to CDC or all new arrangements for Home Care Packages. NCOSS recommends that all arrangements for Home Care Packages, including subsidy and fee arrangements, are subject to evaluation. It will be difficult for the evaluation process to isolate changes or developments that are solely the result of CDC without also assessing the effects of other arrangements.

The evaluation process should consider how all arrangements contribute to the program as a whole. Furthermore, as the proposed amendments to the *Aged Care Act 1997* in the *Aged Care (Living Longer Living Better) Bill 2013* and other bills introduced to Parliament in March 2013 require a review of the changes five years after the passage of the Bill, data collection and the evaluation of the Home Care Packages program will be important evidence toward that review.

NCOSS has made a number of recommendations about the evaluation process throughout this submission. A number of provisions throughout the draft Guidelines will have an effect on waiting lists. NCOSS is particularly concerned about waiting lists, as the Productivity Commission identified that waiting times for an Aged Care Assessment Team (ACAT) assessment, and then for a service after assessment, had tended to increase over time.[14] The effect of implementing new package levels at 1 and 3 must be assessed for the impact on waiting times and waiting lists, and whether the intended effect of reducing unmet demand has been achieved.

The scope and nature of change in implementing CDC must also be thoroughly evaluated. NCOSS is particularly concerned about the nature of decision-making support available to consumers, and the approach providers take to supporting consumers to make choices and navigate options. This requires particular skill, and NCOSS recommends that the evaluation process develop quality indicators to measure the sector's capacity, and any changes over time, in this area.

NCOSS also notes that the evaluation of the CDC pilot initiative did not involve many Aboriginal participants, and there was a lower proportion of participants from culturally and linguistically diverse communities than in non-CDC packaged care.[15]

NCOSS also recommends that the evaluation pays close attention to the impact of brokerage and sub-contracting on quality, availability, and quantity of services, and the financial impact for consumers. NCOSS would suggest this should occur with a view to establishing a cap on administrative costs associated with sub-contracting.

Recommendations

21. That the evaluation of the Home Care Packages program is independent of DoHA.
22. That the evaluation of the Home Care Packages program includes evaluation of all new arrangements, including new fee and subsidy structures, processes for ACAT approval, and waiting list management.
23. That the evaluation of the program includes an assessment of:
    - the impact of broad banding of assessments on prioritisation;
    - the capacity of providers to undertake decision support;
    - specific attention on impact of CDC on Aboriginal and Torres Strait Islander and culturally and linguistically diverse consumers, and their families and carers;
    - the impact of brokerage/sub-contracting;
    - whether the Home Care Standards reflect the objectives and aims of the program;
    - if it is retained, the impact on CDC of the specified list of services; and
    - interface issues with other programs.

Part C – Accessing a Home Care Package

2.3 Assessment by an Aged Care Assessment Team

NCOSS supports the current arrangements for face to face assessments by Aged Care Assessment Teams (ACATs). However, current funding agreements for ACATs end on 30 June 2014. NCOSS understands that DoHA is considering future arrangements for assessments for aged care services.

NCOSS strongly supports in person assessments, particularly for people who have complex or high support needs. Furthermore, in person assessment is often the most appropriate for people with 'special needs' including Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse communities, people with mental health conditions and people at risk of homelessness. The NSW Aboriginal Community Care Gathering Committee recommends that Aboriginal workers must be involved in ACAT assessments for Aboriginal and Torres Strait Islander consumers, and any non-Aboriginal workers involved in assessment must be trained to work with Aboriginal and Torres Strait Islander people.[16]

Recommendation

24. That any assessment process for Home Care Packages involves face to face assessment, preferably in the person's home.

3.2 When a package may not be appropriate

While NCOSS understands that other programs, such as the Transition Care Program, are available for some short term interventions, the prohibition on using Home Care Packages for short term support contradicts the overall emphasis of the Home Care Packages program on wellness and re-ablement. Some re-ablement interventions may be of a short term duration, and a person may no longer require ongoing, co-ordinated services as a result. It is in the interests of the program as a whole to allow short term interventioned of this nature.

Furthermore, some consumers have episodic, rather than ongoing, needs for support. This is particularly true for people with mental health conditions. People in these circumstances should not be excluded from accessing a package as a result of having specific needs.

Recommendation

25. That Home Care Packages offering re-ablement interventions can be delivered on a short term basis.

5. Referral from an ACAT to an approved provider

NCOSS is concerned at the continued provision for ACAT to directly refer a consumer to a provider may limit the choice available to the consumer. NCOSS suggests that, where more than one package is vacant in an area, ACATs should always offer information about alternatives.

[16] NSW Aboriginal Community Care Gathering Committee (2012) *Challenge, Change and Choice Policy Position*, Sydney, ratified June 2011, p. 21.

NCOSS has heard a number of cases where an Aboriginal person or a person who does not speak English as a first language is referred to a particular provider directly because that provider identifies with the community that the person is purported to be part of. This is not always appropriate, as there may be personal, cultural or community issues which may be a barrier to the person receiving appropriate support from that provider. A person must always be supported to exercise choice where options are available.

Recommendation

26. That the draft Guidelines are amended to state that ACATs should always offer information about the variety of options available to the consumer.

6. Being offered a package by an approved provider

NCOSS appreciates the resource constraints which may require a person who is assessed for a higher-band package (Level 3 or 4) to be allocated a lower-band package because no others are available. However, NCOSS has a number of concerns about this process and the appropriateness of lower band packages for people who are assessed as having a higher level of need.

NCOSS is concerned that a person assessed as needing a high level of support, particularly clinical care, may not have access to those supports through a lower-band package. Alternatively, they may need to top up the lower level package significantly in order to access the level of support that is appropriate. This may then have financial implications for the consumer and the provider. NCOSS recommends that the evaluation of the program assesses the clinical and financial impact for people who receive a lower package than they are assessed as needing.

NCOSS is particularly concerned that people who are approved for a higher band package, and are allocated a lower band package, may then be a lower priority for a higher band package when it becomes available. This may be appropriate, however the lack of consistency in waiting list management across NSW also results in inconsistent outcomes and a lack of systematic data about allocations. Some areas have waiting lists managed by ACATs, and in others approved providers all manage their own waiting lists. NCOSS' stakeholders agreed that waiting list management by ACATs results in more consistent outcomes in allocating packages. NCOSS therefore recommends that the Guidelines are amended to specify that ACATs must be involved in prioritisation and waiting list management for Home Care Packages.

This will allow data collection about approvals, waiting lists and prioritisation which can then be compared across Australia for the evaluation of the program. NCOSS recommends that the effects of introduction of package Levels 1 and 3, and broad-banding of approvals, is evaluated for its impact on waiting lists.

NCOSS is concerned, however, that ACATs are not resourced to manage waiting lists, and this would be an additional task. NCOSS also recommends that ACATs are resourced to undertake waiting list management.

On a broader scale, broad-banding of assessments and the introduction of packages at Levels 1 and 3 will require revision of the planning framework for Home Care Packages to ensure that higher level packages are available in areas where there are consumers who have been approved for a higher level package but are receiving a lower level package.

Recommendations

27. That the evaluation of the program assesses the clinical and financial impact for people who receive a lower package than they are assessed as needing.
28. That ACATs must be involved in prioritisation and waiting list management for Home Care Packages.
29. That ACATs are specifically resourced to undertake waiting list management.

Part D – Making Use of a Home Care Package

2. Home Care Agreement

2.1 Overview

NCOSS is also deeply concerned about the lack of discussion about translation and interpreting services in the draft Guidelines except at sub-section 2.1 of Part D in the draft Guidelines. For consumers who do not speak English as a first language, translating and interpreting services are critical to ensuring the success of support. It is likely that under a CDC model, consumers who do not speak English as a first language will require more extensive translation and interpreting services than under a non-CDC package. It is possible that a substantial proportion of the budget will be taken up in paying for translation and/or interpreting services, particularly for lower level packages. This is inequitable, particularly as people not born in English speaking countries already experience barriers to accessing support, and have disproportionately low levels of use of aged care services.[17]

The NSW Aboriginal Community Care Gathering Committee also highlights that, while people who do not speak English as a first language have access to language interpreters, Aboriginal and Torres Strait Islander workers act as cultural interpreters for Aboriginal communities. The cultural interpretation that Aboriginal workers, and bilingual and multicultural workers, undertake is not acknowledged or recognised, often resulting in considerable increased workload for those workers. NCOSS recommends that Aboriginal and Torres Strait Islander consumers and consumers from culturally and linguistically diverse communities can access a **language and cultural supplement** to ensure that they do not experience reduced levels of service because a service provider does not have in-house capacity to communicate with them appropriately.

Recommendation

30. That a language and cultural supplement is introduced and made available to Aboriginal and Torres Strait Islander consumers and consumers from culturally and linguistically diverse communities to assist with any language or cultural interpretation and support that people from these communities may need.

2.2 Items to be included in the Home Care Agreement

NCOSS supports the increased transparency involved with inclusion of the care plan and an itemised statement of fees payable in the Home Care Agreement. In accordance with a person centred approach, NCOSS recommends that the *Charter of Rights and Responsibilities for Home Care* is included as part of every Home Care Agreement, rather than only provided to the consumer. Without inclusion in the Home Care Agreement, the

[17] Steering Committee for the Review of Government Service Provision (2013) *Report on Government Services 2013*, Productivity Commission, Canberra, Table 13A.32.

Charter is not always enforceable nor would a consumer have recourse to the Charter where they believe it has not been upheld.

The consumer's rights with respect to transparency of the budget should also be recorded in the Agreement. This includes rights with respect to unspent funds and any planned contingency.

Recommendations

31. That the Charter of *Rights and Responsibilities for Home Care* is included as part of every Home Care Agreement.
32. That the consumer's rights with respect to transparency of the budget should also be recorded in the Agreement. This includes rights with respect to unspent funds and any planned contingency.

2.3 Cases where the consumer does not want to sign the Home Care Agreement

NCOSS supports the requirement for an approved provider to continue to provide services to the consumer where the consumer does not want to sign a Home Care Agreement. NCOSS is aware of situations where consumers have refused to sign paperwork with a service provider due to concerns about privacy and a history of information abuse. Continuing to support consumers in these circumstances is vital to ensuring that disadvantaged population groups continue to access support.

3. Packages delivered on a CDC basis

3.1 Care Planning

NCOSS supports the broad scope of goal setting suggested for the care planning process. NCOSS suggests references to the CDC principles in section 3.2 in Part A of the draft Guidelines would be useful at this point to illustrate how those principles may be implemented in practice. Examples of superior practice in goal setting and planning supports would assist improved practice in this process. Under a person centred approach, planning and decision-making are ongoing, involving continuous engagement between the person and the provider to ensure that support is responsive to the person's goals and aspirations, which can change over time.

NCOSS also suggests that the Guidelines include a discussion about supported decision-making, and techniques that may assist people who need additional support to make decisions, for example, a person with dementia who has no carers.

3.1.3 Level of consumer control over the management of the package

In the delivery of support, control does not always manifest as independent management over administrative and technical matters. Rather, NCOSS suggests that control is a qualitative matter involving the exercise of autonomy in decision-making and planning. A person may have very little control while taking on a range of tasks to manage supports, or may have a great deal of control while undertaking no such tasks.

NCOSS is concerned at the emphasis upon administrative management in this section. A range of supports will be needed across the Home Care Packages program to ensure that all consumers can exercise control. How this manifests will be different for each person.

NCOSS recommends that this sub-section is deleted from the Guidelines, as it is reductive and misrepresents the notion of control as merely administrative. NCOSS recommends that it is replaced with a discussion of supported decision-making, while also specifying that the budget must reflect the level of management and administration being undertaken by the consumer.

Recommendations

33. That sub-section 3.1.3 'Level of consumer control over the management of the package' in Part D, is deleted from the Guidelines and replaced with a discussion of supported decision-making.
34. That the Guidelines specify that the budget for a Home Care Package must reflect the level of management and administration being undertaken by the consumer.

3.1.4 Determining who has authority to make decisions

Decision-making, in a legal sense, is context- and decision-specific. That is, capacity to make decisions is dependent on the decision and the situation of the person at the time the decision is being made. Legal determinations about capacity are also specific and differ in each State and Territory. In all cases, a person must be assumed to have capacity until it can be demonstrated that they do not have capacity. NCOSS is concerned that these draft Guidelines make specific reference to substitute decision-making without discussing the legal or social context of those decisions and with no discussion about supported decision-making. Providers will have specific legal obligations relating to decision-making in each jurisdiction. NCOSS recommends that this sub-section is deleted from the Guidelines.

Recommendation

35. That sub-section 3.1.4 is deleted from the Guidelines.

3.1.5 Case management

While NCOSS recognises the importance of many of the roles of case managers and care co-ordinators outlined in the draft Guidelines, many of the activities and skills of case managers are not recognised. Case management that takes a person centred approach involves more than assessment, goal identification and monitoring. It involves supporting a person to work towards their strengths, identifying creative solutions, and supporting a person to think about the possibilities for their wellbeing. NCOSS recommends that this sub-section is broadened with best practice examples of case management from a person centred approach.

Recommendation

36. That sub-section 3.1.5 'Case management' in Part D is broadened with best practice examples of case management from a person centred approach.

3.1.8 Giving effect to the consumer's choices and preferences

NCOSS is concerned at the emphasis in this sub-section on avoiding risk to the consumer. Part of ensuring a person centred approach is balancing risk with the right of the person to exercise autonomy and choice about the supports under consideration. The flexibility

offered by CDC should offset many risks, as a consumer is no longer necessarily locked in to a specified program of services, and may change their plan and budget. The *Charter of Rights and Responsibilities for Community Care* also specifies that consumers have a responsibility “to accept responsibility for [their] own actions and choices even though some actions and choices may involve an element of risk”.

Allowing a person to take risks means they can take advantage of opportunities and may grow. Even making a mistake may offer learning opportunities and have its own rewards. There are options, in the disability sector for example, of tools and mechanisms that can manage risk to the person, while ensuring they can access opportunities. NCOSS suggests a discussion of the concept of dignity of risk in this sub-section.

Recommendation

37. That sub-section 3.1.8 in Part D refer to the rights of the consumer to take risks, and discuss the concept of dignity of risk.

3.1.9 Sub-contracted or brokered services

NCOSS supports the capacity of approved providers to deliver support more flexibly through sub-contracting. However, NCOSS is aware that sub-contracting arrangements may not always be in the best interests of the consumer. NCOSS is aware of other programs in which sub-contracting arrangements have significantly reduced the overall amount of service provided to the person, resulting in risks to their wellbeing.

NCOSS suggests that the Guidelines include a notional cap on administrative costs associated with sub-contracting within Home Care Packages, from which a consumer may opt out if the provider has explored all other alternatives or if there are limited options. This aspect of CDC must be evaluated for the overall effect upon the amount of service delivered to consumers.

Once again, the entitlement model proposed by the Productivity Commission would avoid many of the risks of sub-contracting, as the provider would be accountable to the consumer and the consumer would be able to avoid some administrative costs.

Recommendation

38. That the evaluation of the Home Care Packages program assesses the impact of sub-contracting on costs, and the impact on the quality and quantity of services available to consumers.

3.1.11 Contracting to informal carers, family members or friends

NCOSS supports increased flexibility for consumers through paying family, friends or carers to provide support. All requirements and accountability in relation to the workforce would also remain in place, including offering training opportunities, Award wages and working conditions, and Workplace Health and Safety. With appropriate measures in place, engaging family members, friends or carers on a paid basis may actually enhance the quality of service and better meet the person’s goals.

However, in some cases, due to cultural or family obligation, a family member or carer may not accept the wages or working conditions of paid care workers. In these cases, Home Care Packages must also allow a consumer to compensate a carer by other means. Culturally appropriate safeguards against abuse are also critical to ensuring the effectiveness of provisions for engaging family members or carers on a paid basis.

NCOSS does not support the notion that family, friends or community members who provide support to people who are frail, have disability or are unwell are "informal" carers. The *Carer Recognition Act 2010* excludes care workers and volunteers from the definition of a carer.[18] NCOSS recommends that the word "informal" is deleted from the Guidelines when used in reference to carers.

Recommendation

39. That the word "informal" is deleted from the Guidelines when used in reference to carers, in accordance with the *Carer Recognition Act 2010*.

3.2 Individualised budget

3.2.2 What is an individualised budget?

NCOSS supports the inclusion of a transparent individual budget for consumers.

However, NCOSS is deeply concerned at the inclusion of advocacy amongst allowable administrative expenses for an individual budget. Individual advocacy for aged care consumers is provided by the National Aged Care Advocacy Program (NACAP), which is a separately funded program under the *Aged Care Act 1997*. NACAP services are free for consumers of aged care services. A provider must not be allowed to charge the consumer from their package for provision of a service which is already freely available to them. Furthermore, it is impossible for a service provider to advocate for their own client, as doing so is an inherent conflict of interest. NCOSS strongly recommends that this provision is deleted from the Guidelines.

Recommendation

40. That the provision to fund advocacy from a Home Care Package as an administrative cost is deleted from the Guidelines.

3.2.3 Contingency

NCOSS supports the provision to plan for a contingency in a budget for emergencies or unplanned expenses. The definition of a contingency in the draft Guidelines, however, is ambiguous in relation to some matters. The definition of a contingency should not include planned savings for later expenditure, for example on a large piece of equipment, nor should it include unplanned savings as a result of sound management of the budget. A consumer should be allowed to retain any savings in addition to the contingency.

Recommendation

41. That the definition of a contingency includes only a planned contingency, and not planned savings for later expenditure, or unplanned savings. Consumers should be able to retain any savings in addition to the planned contingency.

[18] FaHCSIA (2010) *Carer Recognition Act 2010 Guidelines*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Canberra, p. 4.

3.2.5 Unspent funds when a consumer leaves a package

NCOSS is concerned about the provision for providers to retain unspent funds in a package if a person moves to a different provider. In most cases, a provider has no incentive to negotiate a transfer of the unspent funds, or any contingency. For consumers who had planned to purchase costly items, or had been saving towards later expenditure, this may be particularly difficult.

This sub-section is also ambiguous as to the budget for a consumer who moves from one provider to another. In most cases, it would be reasonable to assume that the full annual budget for the level of package that the consumer transfers to would not be available. In such cases, transfer of the unspent funds would be more critical for the consumer to ensure continuity in their support arrangements. As many consumers would be likely to move due to increased support needs, not being able to retain unspent funds may be a risk to the health and/or safety of the consumer.

NCOSS recommends that providers are required to transfer unspent funds to any new package when a consumer leaves a Home Care Package.

The planning framework limits the portability of packages, and, in turn, results in a provider-centred rather than person centred system. Under a person centred arrangement, a person would have full portability, and any resource allocation for their support would respond to additional needs, for example, if the person needed to move to a more remote location resources would be commensurate with the costs of supporting the person in that location.

Recommendation

42. That providers are required to transfer unspent funds to any new package when a consumer leaves a Home Care Package.

Part E – What Home Care Packages Provide

2. Care and Services

NCOSS is concerned that this section of the draft Guidelines may undermine the choice and control afforded by Home Care Packages being delivered according to a CDC approach. Retaining a list of specified services for packages delivered on a CDC basis, while consumers and service providers can also negotiate to extend those services, is a confusing and contradictory approach. NCOSS is also concerned that the list of excluded services and items at section 2.3 is overly prescriptive and prohibitive for a CDC approach, where a consumer's care plan and goals will be the primary determinants of supports purchased from a package. Many excluded items would have a strong clinical justification or supportive effect which could be demonstrated.

Providers who participated in the CDC pilot initiative from 2010 onwards did have to reconcile approaches to delivering support that were in tension with one another. NCOSS has heard that many providers who participated in the CDC pilot initiative converted all other packages into CDC packages to resolve this tension. A specified list is likely to limit both providers who are not as well-placed, as well as providers more experienced, in delivering CDC. It is likely to cause confusion, to which providers are likely to respond by managing risk to the provider through reducing choices available to consumers. A specified list provides no guidance about an effective CDC approach.

NCOSS recommends that sub-sections 2.1.3, 2.2.3 and 2.3 apply to non-CDC packages only, and that DoHA establishes an exclusion approach for CDC packages. Illustrative examples of creative, innovative and flexible use of packages to meet a consumer's needs

and achieve their goals would be a more useful indicator to providers about how to deliver a Home Care Package.

NCOSS has heard that the rationale for maintaining lists of specified services is that these are required by legislation. However, there is no requirement for a specified list of services in community care or flexible care in the *Quality of Care Principles 1997* or the *Aged Care Act 1997*. Even if such constraints were apparent in the legislation, the amendments to the *Aged Care Act* and associated legislation contained in the 5 bills that came before Parliament in March 2013 offer the opportunity to ensure legislative support for consumer choice and control.

Recommendations

43. That sub-sections 2.1.3 and 2.2.3 of Part E apply only to non-CDC packages.
44. That illustrative examples of innovative and creative use of a package are included in the Guidelines.

2.1 Home Care Levels 1 and 2

2.1.3 Inclusions

NCOSS is concerned at the inclusion of advocacy amongst allowable support services for Home Care Levels 1 and 2. Individual advocacy for aged care consumers is provided by the National Aged Care Advocacy Program (NACAP), which is a separately funded program under the *Aged Care Act 1997*. NACAP services are free for consumers of aged care services. A provider must not be allowed to charge the consumer from their package for provision of a service which is already freely available to them. It is impossible for a service provider to advocate for their own client, as doing so is an inherent conflict of interest. NCOSS recommends that this provision is deleted from the Guidelines.

Recommendation

45. That the provision for a Home Care Package to fund advocacy is deleted from the Guidelines, as advocacy is available to all consumers of Commonwealth aged care programs through the National Aged Care Advocacy Program.

2.2 Home Care Levels 3 and 4

2.2.3 Inclusions

NCOSS suggests that the definition of ‘emotional support’ under sub-section *C. Support Services* is amended. The current definition, which is identical to the definition in the current *Community Packaged Care Guidelines* for EACH packages, reflects an outdated approach to ageing, which conceives of ageing as a continual process of declining functioning and dependency, with dependency implicitly conceived as negative. In accordance with wellness and re-ablement approaches, and in recognition of the positive role of interdependent relationships of trust and caring that frail older people have with others in their lives, NCOSS recommends amending this definition.

Recommendation

46. That the definition of 'emotional support' in the Guidelines is updated to reflect a positive view of ageing, caring relationships, and in accordance with wellness and re-ablement approaches.

2.3 Excluded services and items

The list of excluded items and services at this sub-section is extensive and the rationale for many of the exclusions is not clear, particularly where some excluded items are provided by other government subsidised programs for which there are interface arrangements in place.

For a CDC approach, some of the supports in the list of exclusions would be the most effective means of achieving the goals of the consumer and delivering the care plan. For instance, subsidising entertainment activities or travel and accommodation may also have a respite effect for a person's carer.

Furthermore, for consumers in financial hardship, support to maintain their housing may be the most appropriate use of the package at a particular point in time. This would particularly be the case for people in the private rental market or marginal housing who are at risk of homelessness, or older people subject to financial abuse. While NCOSS appreciates that Home Care Packages are intended to provide ongoing support relating to a person's frailty or disability, categorically excluding rental or mortgage assistance may have an adverse effect on the health and safety of the consumer. NCOSS suggests that it would be more appropriate to exclude paying for permanent accommodation in the long term rather than all financial assistance with accommodation.

NCOSS is also concerned at the exclusion of food from allowable purchase. While notionally a person's income is intended to support a person's nutritional needs, purchase of food through, for example, cost recovery to a Meals on Wheels provider would be excluded under this provision. Where many older people are at risk of malnutrition due to increases in the cost of living[19], purchase of food through a Home Care Package may be essential to maintaining their health and wellbeing. Frail older people who have difficulty shopping and preparing food may be assisted more effectively through home delivered meals than by engaging paid workers to assist with shopping, transport and meal preparation. Subsidising some food costs would be an appropriate use of a Home Care Package subsidy consistent with the consumer's care plan.

NCOSS also questions the exclusion of customised aids and motorised wheelchairs. While these items may be costly, a consumer may choose to plan savings in their budget to purchase such equipment over time. The draft Guidelines offer greater scope for Home Care Packages at all levels to finance equipment purchases. It is therefore overly restrictive to exclude motorised wheelchairs or customised aids from the scope of the Home Care Packages program.

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[19] Rist, G., Miles, G. & Karimi, L. (2012) 'The presence of malnutrition in community-living older adults receiving home nursing services' in *Nutrition & Dietetics*, Vol. 69, pp. 46–50.
National Seniors Productive Ageing Centre (2011) *Are Older Australians Being Short-Changed? An Analysis of Household Living Costs*, Canberra, November.

Recommendations

47. That any services or items that can be demonstrated to support a person to achieve goals as stated in their care plan are not excluded from a Home Care Package.
48. That payments for assistance with accommodation costs, travel, entertainment, food, customised aids and motorised wheelchairs are deleted from the list of excluded services and items.

3. Security of tenure

3.1 Consumers moving locality

NCOSS supports full portability of supports for those needing them. Within the current planning framework for Home Care Packages, portability is severely limited and a person may not be able to continue supports if they move location.

Many frail older people are likely to need to move location on a short term basis due to illness or injury, for instance, staying with a family member while they recover from surgery. Short term relocation should not jeopardise a consumer's security of tenure or continuity of their supports. NCOSS recommends that providers are required to maintain continuity of support where a consumer moves locality for a short term or fixed duration.

NCOSS reiterates the recommendation above that DoHA simplifies the process of transferring places from one provider to another to ensure that consumers moving locality have greater security of tenure and continuity of supports.

Recommendation

49. That providers are required to maintain continuity of support where a consumer moves locality for a short term or fixed duration.

3.2 Other reasons for terminating a package

The other reasons for terminating a package under the *User Rights Principles 1997* are concerning to NCOSS. Under changes to arrangements for fees and subsidies proposed in the *Aged Care Act (Living Longer Living Better) Amendment Bill 2013* it is likely that consumers will be required to pay higher fees. The provision for a provider to terminate a package if "the consumer cannot be cared for at home with the resources available to the approved provider" is highly ambiguous in these circumstances. NCOSS cautions that this must not include where a consumer is unable to pay fees, or is in the process of applying for a hardship supplement due to experiencing financial hardship. This is consistent with section 7. d) of the *Charter of Rights and Responsibilities for Community Care* which specifies that a consumer has the right "not to be denied care and services because of [their] inability to pay a fee for reasons beyond [their] control."

Recommendation

50. That financial hardship is not a reason to be denied security of tenure in a Home Care Package.

4. Leave Provisions

NCOSS supports consistency of leave provisions across Home Care Packages. Under the proposed changes to the *Aged Care Act 1997*, a consumer on leave from a package for 28 days or more, after 1 July 2014, will be transferred to the new arrangements for fees and subsidies. NCOSS considers that any person who transfers to the new arrangements should also be offered the opportunity of converting their package to a CDC package.

Current arrangements for leave also allow providers to continue to charge fees to a consumer on leave from a package. NCOSS considers this unfair, particularly where a person will be paying both a basic daily fee and an income tested fee. For a person who is on leave from a package due to hospitalisation or recovery from hospitalisation, it is likely they will be liable for multiple fees, while the Home Care Provider is likely to be able to reduce costs due to suspending ongoing services for the period of leave. NCOSS recommends that any consumer on leave from a package for more than 7 days should be charged a reduced fee, or the basic daily fee should be suspended during the period of leave.

Recommendation

51. That any consumer on leave from a package for more than 7 days should be charged a reduced fee, or the basic daily fee should be suspended during the period of leave.

Part F – Rights and Responsibilities

2.1 Rights and responsibilities

While NCOSS supports the current *Charter of Rights and Responsibilities for Community Care*, some changes may be necessary in order to fully support a CDC approach.

Recommendation

52. That the *Charter of Rights and Responsibilities for Community Care* is amended as follows:
    - Section 1. a) currently states “to be treated and accepted as an individual, and to have my individual preferences respected.”
      This should be amended to state “to be treated and accepted as an individual, and to have my individual preferences supported.”
    - Section 2. a) currently states “to be involved in identifying the community care most appropriate for my needs.”
      This should be amended to state “to identify goals for myself and use my Home Care Package to achieve those goals.”
    - Section 2. b) currently states “to choose the care and services that best meet my assessed needs, from the community care able to be provided and within the limits of the resources available.”
      This should be amended to state “to make choices about how, why, when, where and by whom support is provided to meet my assessed needs and achieve my identified goals, within the resources available.”

2.2 Advocacy

NCOSS notes that the National Aged Care Advocacy Program (NACAP) is being expanded under the *Living Longer. Living Better.* aged care reforms. NACAP services already provide advocacy to consumers of CACP, EACH and EACH-D packages. NCOSS recommends that DoHA conduct specific consultations with NACAP providers in each State and Territory about the likely effect of the Guidelines for the Home Care Packages program on the rights of consumers. NCOSS is particularly concerned about the capacity of the Aged Care Complaints Scheme (see below) to address complaints relating to CDC, particularly the approach of a provider to delivering person centred support under a CDC framework.

Current NACAP organisations have extensive experience with the Aged Care Complaints Scheme, and can provide valuable feedback about how the Aged Care Complaints Scheme may be improved. Due to the short time frame for providing feedback about these draft Guidelines, NCOSS was not able to consult the NACAP funded organisation in NSW, The Aged-Care Rights Service Inc. (TARS).

Recommendation

53. That DoHA specifically consult NACAP funded organisations across Australia about the draft Guidelines before they are finalised.

2.3 Complaints

NCOSS is concerned about whether the current Aged Care Complaints Scheme is equipped to address complaints relating to Home Care Packages, particularly with regard to CDC.

The Scheme currently operates from the Office of Aged Care Quality and Compliance within DoHA. NCOSS believes it is imperative that the Aged Care Complaints Scheme is independent of DoHA, as this would increase trust in the decisions of the Scheme by both consumers and providers. In 2009, Merilyn Walton completed a review of the then Aged Care Complaints Investigation Scheme and recommended establishment of a new Aged Care Complaints Commission, separate from the Department of Health & Ageing.[20] This is the standard structure for Health Care Complaints Commissions across Australia. The Productivity Commission echoed this recommendation in its *Caring for Older Australians* Inquiry Report.[21]

Concerns about the independence of the Scheme from resource allocation and policy decisions within the Department may become amplified where a consumer may make a complaint about the allocation process for a Home Care Package. For instance, a consumer who is approved for a Level 3 package, who is then offered a Level 2 package due to lack of available packages at the appropriate level in the area, may then not be prioritised for a Level 3 package when it becomes available. In the event that the consumer complains, it would be a conflict for DoHA, the agency managing the Aged Care Approvals Round through which places are allocated, to also make a determination about the prioritisation process and waiting list management in the relevant area.

[20] Walton, M (2009) *Review of the Aged Care Complaints Investigation Scheme*, for the Department of Health and Ageing, available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-review-cis-09.htm (last accessed: 24 April 2013).
[21] Productivity Commission (2011), Op. cit., pp. 410-421.

NCOSS is also concerned that the nature of complaint handling will be transformed due to the increased flexibility offered by a CDC approach. Where a Home Care Agreement has the scope to include a flexible and creative care plan, the Complaints Scheme will need to be able to ensure that the rights of the consumer are upheld, but also that the consumer is able to exercise choice and control in the delivery of the package. NCOSS is not confident that the Aged Care Complaints Scheme is staffed with appropriately skilled officers who can determine matters about the quality of practice in supporting consumer decision-making and wellbeing.

Recommendation

54. That the Aged Care Complaints Scheme is reviewed for its capacity to respond to Consumer Directed Care.

Part G – Consumer Fees

The table under section 2. states that "the maximum fee is 17.5 per cent of the basic rate of the single pension; this applies to both single and married consumers". This is identical to the fee provisions in the current *Community Packaged Care Guidelines*. However, the *Aged Care (Living Longer Living Better) Amendment Bill 2013* refers, in section 52D-2, to the basic pension amount. The basic pension amount is determined with reference to the person's circumstances. A member of a couple would not be able to be charged up to 17.5% of single rate pension – the basic daily fee would be up to 17.5% of the *basic age pension amount* as defined in the *Social Security Act 1991*. NCOSS recommends that this is amended to ensure compliance with legislation.

NCOSS also recommends that fees for services provided under the Home and Community Care (HACC) Program and the Commonwealth Home Support Program are included in the annual and lifetime caps on care fees. NCOSS has heard numerous reports that people using HACC services refuse CACPs and EACH packages due to the differential fee structure and higher fees. NCOSS is concerned that this effect will be intensified if HACC and Home Support Program fees are not included in the annual or the lifetime caps on care fees. Particularly in the first year, where a person may have already contributed significant amounts in fees for HACC services, being liable for up to $5000 in care fees for the remainder of the year, as well as a basic daily fee, would be a significant deterrent to a person accepting a Home Care Package. This would then increase demand for HACC services.

NCOSS is particularly concerned for the impact of changes to fee and subsidy arrangements on low income part pensioners, who will be required to pay 50 per cent of their income above the relevant threshold in care fees, up to the value of the annual cap. NCOSS is concerned that this will cause undue hardship for low income people. UnitingCare Australia, in their submission to the Senate Community Affairs Committee Inquiry into the aged care reform bills, demonstrated that lower income part-pensioners would face a more significant financial impact as a result of fees than those on a higher income. NCOSS recommends that DoHA models more progressive fee structures which would have a lesser impact on low income part-pensioners.

Recommendation

55. That DoHA undertakes modelling of more progressive fee structures which would have a lesser financial impact on low income part-pensioners.

Part H – Supplements

1.1 Dementia and Veteran's Supplements

NCOSS recommends that a person should not require a formal diagnosis of dementia to access the dementia supplement. Obtaining a timely diagnosis of dementia is difficult for many older people, and, on average, 3.1 years pass between first noticing symptoms and accessing a formal diagnosis.[22] Requiring a formal diagnosis for dementia support through the dementia supplement may cause delays resulting in the deterioration of the person's wellbeing and that of their carer/s and/or family.

The HACC Program does not require a formal diagnosis before specialised dementia supports are put into place, and supports this approach being extended to the dementia supplement for Home Care Packages. A range of validated screening tools are available that can provide a cognitive assessment in addition to a functional assessment. NCOSS notes that the development of a National Assessment Framework for aged care is progressing this matter.[23]

Recommendation

56. That a formal diagnosis is not required for a person to access the dementia supplement to their Home Care Package.

1.2 Oxygen supplement

NCOSS notes that the oxygen supplement involves a fixed cost structure assuming a certain level of activity and social participation on the part of the consumer. NCOSS is concerned at the capacity of the current oxygen supplement to address the consumer's identified goals in their care plan where a fixed cost structure is in place, particularly where the consumer is socially isolated. NCOSS suggests that this cost structure is reviewed and evaluated in the process of implementing CDC.

Recommendation

57. That the oxygen supplement is reviewed for its compatibility with a CDC approach.

Other matters: Hardship supplement

Section 48-10 of the *Aged Care Act (Living Longer Living Better) Bill 2013* provides for a hardship supplement for Home Care. NCOSS is extremely concerned that there is no mention of the hardship supplement in the draft Guidelines. The current *Community Packaged Care Guidelines* refers to the definition of a person experiencing financial hardship in section 4.4 of the *Allocation Principles 1997*.

[22] Phillips, Jill, Pond, Dimity & Goode, Susan (2011) *Timely Diagnosis of Dementia: Can we do better?*, University of Newcastle, Alzheimer's Australia Paper 24, available at: http://www.fightdementia.org.au/common/files/NAT/Timely_Diagnosis_Can_we_do_better.pdf (last accessed: 19/12/2012).
[23] Sansoni J, Samsa P, Owen A, Hasan, H, Eagar K (2012) *A Model and Proposed Items for the New Assessment System for Aged Care*, Centre for Health Service Development, University of Wollongong.

NCOSS notes that there are current guidelines for determining financial hardship and eligibility for the hardship supplement for residential aged care recipients. However, no such guidelines exist for Home Care Packages.

NCOSS is concerned at the effect of fee levels on older people living in rental accommodation, either renting privately or in social housing, who already pay a significant proportion of their income towards housing costs. Most older people living in rental accommodation pay a significant proportion of their income towards housing costs and are at significant risk of housing stress.[24] NCOSS is also aware of many older Aboriginal and Torres Strait Islander people who support family members who are not dependents of the older person, as a matter of kinship and community obligation. Determinations of financial hardship must allow for the Secretary to take into account the housing, health care, utilities, and other costs affecting the person, including costs associated with supporting other family members (who may not be dependents).

Recommendation

58. That any determinations of financial hardship by the Secretary must take into account housing, health care, utility, and family related expenses.

Part J – Interface with Other Programs

People may be eligible for a number of supports from various programs resulting from their place of residence or other personal circumstances. There is a lack of consistency for interface issues with other programs for supporting people to live in the community. NCOSS notes that there may be legislative barriers, such as with the National Disability Insurance Scheme (now called DisabilityCare Australia) to consistency of interface with Home Care Packages. However, this should be the exception and where barriers are regulatory, should be brought into alignment.

NCOSS considers that as a general principle, a Home Care Package should meet all the needs of the consumer. In accordance with the aim of the *Living Longer. Living Better.* aged care reforms to implement a seamless and continuous system of supports, a consumer should not have to seek supports from other programs in order to supplement supports funded from a Home Care Package. However, without an entitlement system and with the maintenance of limited allocations, it may be necessary for consumers to access support from other programs particularly clinical services. Without clinical supports from other programs there may be significant risks to the health and wellbeing of the consumer. Without an entitlement system, NCOSS recommends that exclusion from other programs for consumers of Home Care Packages is minimised. NCOSS recommends that the level of use by Home Care Package consumers of support from other programs is evaluated, as this will provide valuable data about the effectiveness of package levels, the flexibility of the program, and transition between levels.

NCOSS is particularly concerned with the interface between Home Care Packages and the Home and Community Care (HACC) Program, Day Therapy Centres, and Department of Veterans' Affairs (DVA) funded programs.

3. Home and Community Care

The interface between HACC and community packaged care programs (CACPs, EACH, and EACH-D) has been unclear and inconsistent for some time. Particular service types

[24] AIHW (2012) *Housing assistance in Australia 2012*, Cat. no. HOU 266, Canberra, pp. 45-48.

under the HACC Program have significant interface with the CACP, EACH and EACH-D programs which is likely to continue with the introduction of Home Care Packages.

New service type guidelines for HACC funded Home Modification Services in NSW were introduced by NSW Department of Family and Community Services, division of Ageing, Disability and Home Care (ADHC) in June 2012 after a review of Home Modification Services. The review assessed the model of Home Modification Services in NSW and defined each level of modification.

It emerged, after the implementation of the new guidelines, and a new fee policy for Home Modification Services, that there was significant confusion about modifications that could be funded from a CACP, EACH or EACH-D package, and modifications that were to be funded from the HACC Program. The current *Community Packaged Care Guidelines* provide examples of allowable modifications under Commonwealth community care packages, as do these draft Guidelines. Although the Department of Health and Ageing has clarified that CACP and EACH recipients should be treated as eligible for HACC funded home modifications, it remains unclear as to what level of home modification can be funded from a person's CACP or EACH package, and what level must be funded through HACC. After further inquiries with DoHA, no clarification about which modifications were expected to be funded from CACPs, EACH and EACH-D packages was forthcoming. These draft Guidelines offer no solution.

Due to the high cost of some home modifications, NCOSS considers that this must be a priority issue for DoHA to determine. While NCOSS acknowledges that HACC home modification services are the subject of a review by DoHA at present, this matter is specific and may be resolved promptly with a decision from DoHA.

In the longer term, the interface between home modifications funded from the Home Care Packages program and the Commonwealth Home Support Program will need to be determined. The NSW HACC Issues Forum notes that the National Aged Care Alliance advised that Home Care Packages delivered on a Consumer Directed Care basis should not fund major home modifications.[25] How home modifications, particularly major modifications, can be facilitated for people using Home Care Packages will need to be clarified in the development of the Home Support Program, to ensure seamless access for all people requiring home modifications.

HACC funded home modifications have historically been provided to people at a later stage of frailty and/or disability, often after a significant injury. In many cases, opportunities to prevent falls, injuries, and allow people to remain at home with housing adapted to their level of functioning, have been missed due to the limitations of the HACC Program. NCOSS suggests that DoHA revisits the recommendations from the Productivity Commission's *Caring for Older Australians* Inquiry Report regarding home modifications to determine more sustainable solutions.

3.2.2 Accessing HACC services in addition to a Home Care Package

Although NCOSS considers it an important general principle that Home Care Packages should aim to meet all the needs of the consumer, there may be priority issues which override this principle. However, although the draft Guidelines allow for consumers to access HACC services in an emergency, it must be noted that HACC services are not emergency services, and usually cannot respond immediately to a crisis.

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[25] National Aged Care Alliance Home Care Packages Advisory Group (2012) *The Alliance Advice on Phase One Development of Consumer Directed Care (CDC) Home Care Packages*, Canberra, September, p. 6.

NCOSS is also concerned that the list of suggested HACC services additional to a Home Care Package is limited and does not include nursing and allied health services. Nursing particularly may be significant for consumers who require intensive services for a limited period of time due to a health condition. NCOSS also supports access to HACC funded allied health services to reinforce the overall supports being delivered by the Home Care Package.

Recommendation

59. That the Guidelines are amended to note that consumers of Home Care Packages may access HACC funded clinical services in addition to a Home Care Package.

6. Day Therapy Centres program

Allied health supports are difficult to access for many community care programs. Low remuneration and workforce constraints often mean that community care is not an attractive career option for allied health practitioners. Community care clients who require allied health supports often either wait for considerable periods or pay out-of-pocket for private allied health practitioner services.

In this environment it is difficult to see the rationale for Home Care Package consumers being excluded from using funds from the package to pay consumer fees or contributions for Day Therapy Centre services. In many circumstances this may be the most cost effective option, and far more affordable than seeking private allied health services. Using Day Therapy Centre services at full cost recovery might also be a better option for Home Care Package consumers.

For wellness and re-ablement approaches, accessing allied health support is particularly important, and demand is likely to increase over time. At the same time, the allied health workforce is limited. In the interim, the Day Therapy Centres program may be an important supplement to services funded by a Home Care Package.

Recommendation

60. That Home Care Package consumers may use package funds to pay costs of accessing Day Therapy Centre services.

10. Disability programs

As discussed in this section, the Australian Government provides funding for older people with disability who are using specialist disability services. As discussed above under '*Special Needs Groups*', it is not clear how people in these circumstances will be able to relate to the National Disability Insurance Scheme (NDIS, or DisabilityCare Australia), as no person over the age of 65 can make an access request to be a NDIS participant under the *National Disability Insurance Scheme Act 2013*.

At the time of writing this submission, all State and Territory Governments other than Western Australia have made agreements with the Commonwealth Government to fully implement the NDIS from 2016 onwards. This will mean that older people who are using specialist disability services funded by the Australian Government will be in a situation of considerable uncertainty.

NCOSS strongly disputes the assertion in the draft Guidelines that this funding arrangement "enables older people who have been receiving state and territory disability

services to choose whether they wish to continue to access these disability services, or receive aged care services instead, in order to receive care most appropriate to their needs" (p.80).

In reality, neither disability services nor aged care services meet the needs of people with disability who are ageing. The ageing process results in changes to a person's disability-related support needs, which are substantially different to the needs of frail older people without life-long disability. Aged care services cannot and do not support people with disability appropriately.

NCOSS reiterates the above recommendation that DoHA develops a strategy to address the needs of older people with disability, particularly those who will not be eligible for DisabilityCare Australia and will therefore, by default, rely on the aged care system.

14. Department of Veterans' Affairs Programs

As discussed above, NCOSS is concerned at the extensive provision for veterans to access DVA funded programs as well as a Home Care Package. This would suggest that veterans' needs were not being fully met from the Home Care Packages program, and it would also be inequitable for other disadvantaged persons. For instance, many Aboriginal and Torres Strait Islander veterans are not able to access a Veterans Gold Card because they were not legally citizens at the time of their service, and thus they have reduced access to DVA funded programs. People in other 'special needs' groups who have experienced considerable disadvantage over their lifetimes do not have the benefit of being able to access dedicated programs to support them in older age.

NCOSS recommends that DoHA and DVA monitor the use of DVA programs by Home Care Package consumers and that the evaluation of the Home Care Packages program assesses whether the interface arrangements should continue.

Recommendation

61. That DoHA and DVA monitor the use of DVA programs by Home Care Package consumers and that the evaluation of the Home Care Packages program assesses whether the interface arrangements should continue.

Chronic Disease Management programs

There are several State and Territory based chronic disease management programs available, some of which offer clinical support to people living in the community to manage chronic illness. Health services in NSW at times collaborate with community care services to improve chronic disease management for community care clients. NCOSS suggests that this collaboration should be better facilitated through Medicare Locals and State based health authorities collaborating with community care services.

Conclusion

NCOSS appreciates the opportunity to comment on the proposed changes to the *Aged Care Act 1997* and related legislation, and is happy to provide additional comments supplementary to this submission.

For further information please contact Rashmi Kumar, NCOSS Senior Policy Officer, at Rashmi@ncoss.org.au or by telephone at (02) 9211 2599 ext 108.

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