CONSUMER’S VIEWS ABOUT QUALITY
IN HOME CARE PACKAGES

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INTRODUCTION

The full implementation of Consumer Directed Care (CDC) in Home Care Packages occurred from 1 July 2015 following a number of years of pilot projects. Home Care Today has been supporting CDC implementation since late 2013, with the website commencing in mid 2014. Since that time Home Care Today has had contact with consumers through direct telephone and email enquiries, and through the State and Territory COTA’s delivery of Peer Education sessions to 9,165 older people since July 2014.

Recent contact with the advocacy services across Australia has provided a picture of the number and types of enquiries and cases they have been dealing with in relation to CDC implementation. Home Care advocacy cases last year (2014-15) totalled 962, in comparison with the 2013-14 year of 375.\(^1\)

The following is a summary of consumer views expressed in the KPMG Formative Evaluation of CDC (2015)\(^2\):

- Consumers are spending more time to consider their options and the costs, often delaying when the package commences
- For the first time consumers were asking questions regarding their budget
- Transparency was enhanced through monthly budget with 50% of consumers reading them thoroughly
- Consumers do want more choice but are saying that they don’t know what they don’t know. (Service providers are critical to providing this information)
- Most consumers do exercise some limited control over their package (e.g. what time the services are delivered) but not so much by who it is delivered.
- Consumers rated their satisfaction with home care as a 4 or 5 (satisfied or very satisfied), male consumers rated their satisfaction higher
- Some consumers expressed having to fight for certain equipment purchases or other one off expenditure.

The information in this document has been compiled from information from COTA Australia’s contact with Home Care Package consumers, information from the National Advocacy Services and the KPMG evaluation of CDC. The sections on consumer’s views on quality was drawn from these sources as well as the Home Care Today Consumer Consultation Group members.

CDC WHEN IT IS WORKING WELL

Based on workshops run over Australia Home Care Package providers are themselves reporting on changes to consumer and provider behaviour that reflects positively on the principles of CDC. Where CDC is working well providers are reporting:

- interest by the consumer and carers in maximising the value of their package
- engagement by consumers in their plans
- involvement of extended family in the caring of the older person on the package.
- creativity in the plans to meet the needs of the package recipient and providers are thinking more laterally
- sense of self direction by consumers and decreased sense of entitlement
- recognition by all parties about when a level 4 package is no longer adequate
transparency and clear expectations between consumer and provider.

Two women already in receipt of Home Care package spoke glowingly about the flexibility of usage and how to build up credits.

Positive comments were made by a lady about her package saying it was a level 4 and was working well and she had received more help than she expected, and without it she probably could not have stayed living at home.

(Comments from Peer Education sessions)

CURRENT ISSUES WITH THE QUALITY OF HOME CARE PACKAGES

As can be expected with the introduction of a new approach such as CDC, there is still a way to go with the full implementation of the approach. While there will be further changes in February 2017, it is important to consumers that current issues being raised are addressed before then. For providers, an understanding of the core principles of CDC and the ability to implement these in practice will be crucial to their sustainability in a market environment.

While consumers have raised issues about the cost of Home Care Packages, the introduction of consumers fees occurred in July 2014, prior to the full implementation of CDC. However, with consumers contributing more towards their care, the question of value for money is an issue for consumers. Consumers have reported the same or increased charges but reduced hours or services. Consumers complaining about the cost of an hour of care – up to $60 per hour weekdays.

“I am incredulous that the Federal Government would allow direct-care service providers to become millionaires by charging these exorbitant prices, and making their money out of unwitting and vulnerable taxpayers”.

COSTS

In relation to the introduction of CDC from July 2015, and the subsequent transparency of individual budgets, consumers have raised concerns about high administration fees. They have also raised the issue of paying additional brokerage fees (either set-up fees or additional fees per service) in order to get their provider of choice. When consumers discover that administrative charges remain unregulated, this is seen as negligent on behalf of the Government as providers are free to do what they want at the client’s expense.

“Surely the government isn’t throwing $140 at my mother every day without taking any responsibility for whether she receives the care intended”?

Some consumers have reported that the provider is forcing them to pay contingency fees even when the consumer does not want them. There have also been incidents of paying for but not receiving services on public holidays. Access to hardship assistance is reported to be difficult. Some consumers have been told they need to take out public liability insurance policies to have services come into their home.

“Please note that [the provider] have 65 Level 4 Home Care Packages on their books...that is a conservative $1,450,000 just in administration fees they take from these packages, before they charge ‘client’ fees”.

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The more vulnerable the consumers, the higher the case management fees apply, which reduces their brokerage spending overall. This places the consumer in a more vulnerable position.

**INFORMATION**
Making the most of CDC requires consumers to have information about how the system works and the types of assistance available to them. Consumers report receiving inaccurate information from My Aged Care. Some consumers do not understand their case management options, and receive limited information about the options for self-management.

Consumers have raised a number of concerns about Home Care Agreements which they regard as long and complex. Some do not read the agreement and then family members report being unhappy with some clauses, such as the provider having a caveat on people’s homes for non-payment of fees.

Consumers are concerned about the complexity of the income assessment forms. Some consumers report not being able to understand their budget statements or not receiving statements at all. Some consumers are being allowed to exceed their package budget limit without being told and then told they have a debt later on.

One person did all the organising for another with no relatives and was inundated with vast amounts of information/reading matter, endless phone conversations. My Aged Care was not useful. Process is very complicated and very stressful (comment re a Peer Education participant).

**CHOICE AND FLEXIBILITY**
Some consumers report a lack of choice on what they can spend funds on, or that requested items are refused. Some can’t get the carers they want or find it is prohibitively expensive to broker. Issues are often raised regarding the package not covering food.

**CONSUMER AND PROVIDER PARTNERSHIP**
Some consumers have reported that their goals are not reflected in the care plan, or that they have not been involved in care planning. In other situations changes to the package occurred without consultation with the consumer.

Some consumers have reported being pressured, bullied, harassed or intimidated by providers.

“My Case Manager used to be warm and supportive, and is now cold and business-like”

**EQUITY**
Aged care system difficulties for individuals with special needs, and in remote areas were identified.

Lack of trust in "system", government care services, anecdotes relating to experiences of services failure. Concern was expressed that completing the Home Care Agreement was a task beyond many indigenous elderly people, because of various health issues (eyesight, hearing)
Concerns raised about how people with Dementia will be able to participate in CDC-based home care.

Concern of cost of transport using up most of available CDC funding. Transport is a big issue with this rural group and availability of services.

Not enough packages at level required unfairness - one male - wife Level 4 allocated unfairness 12 Hours a week, but wife needs 2 people to lift and care for her - thus he has 6 hours a week.

(Comments from Peer Education sessions)

WHAT DO CONSUMERS CONSIDER TO BE QUALITY IN A HOME CARE PACKAGE?

A fundamental aspect of quality is to understand that consumers and providers come to the partnership with different perspectives. We also need to recognise that families and supporters (who may or may not identify as “carers”) also play a significant role. Consumers rely on providers and other professionals to give them accurate information and unbiased advice about options, but the consumers are generally the best people to judge what will meet their needs and goals. However, many consumers have been in the system for a long time and usually were not offered the opportunity to make decisions about their needs, and accepted what they were told by providers. In the situation where a consumer is particularly frail or vulnerable, those closest to them who have their best interests at heart may be the ones to express their understanding of what the person’s needs and preferences are, if they are unable to express that themselves.

Our experience of what consumers and carers are seeking in relation to Home Care Packages (HCP) under the CDC approach very often comes down to some basic interpersonal expectations. Whilst there seems to be a large focus on the costs and charges associated with HCP, in most cases, the bottom line is that consumers speak about wanting to be genuinely listened to and have their opinions respected. They want genuine, mutually respectful partnerships with their provider, rather than adversarial relationships. They want clear answers to their questions and not to be dismissed when they ask for reasons, justifications or explanations. They want to talk to the same adviser each time and to feel that their needs are understood by someone who has come to know them. They want to trust their adviser and their provider and to feel secure in the knowledge that they are not being hoodwinked or taken advantage of. They do not want to be continually on guard and suspicious of the motives of their adviser or provider.

In addition, consumers want to choose the level of involvement they have in the day to day management of their HCP. We often hear from consumers of HCPs who want to do more for themselves but object to the insistence of the provider that they must still pay high percentages of their package funds for case management and administration costs. Or consumers who seek to have their services provided by external contractors (so that the provider is doing little more than payment of accounts after initial approval of the contractor) and object to administration charges that include salary on-costs for the provider’s staff who are not even part of the package. In future, consumers will be seeking providers who can demonstrate that they will willingly negotiate a lower rate where there is an alternative person to take on greater involvement or where there is no case for the inclusion of costs that are simply not incurred.
Consumers have pointed out the lack of privacy and the conflict of interest that can occur when package providers seek to pressure consumers into using their own employees rather than offering a range of agencies to choose from. Where providers pressure consumers into using the services of their direct employees rather than a sub-contracted agency, there needs to be greater onus on them to guarantee the consumer’s legal right to privacy; the sharing of information in relation to health/care provision should really only be on a need to know basis. It is a feature of the NDIS that case management/package service providers that also want to provide services can only do so if they can prove that there is no conflict of interest and, of course, the individual’s right to privacy needs to be maintained as it would in any health care setting.

COTA Australia has spoken with many consumers about their expectations of what the aged care system should provide and how it should be delivered (including the COTA Conversations on Ageing, 2012). In summary, the service characteristics that consumers have identified that define quality include:

- treating people as citizens first – acknowledging their strengths and contributions, not as “clients” who are a “burden” on the system, remembering that in the near future the provider will need to be chosen by the consumer to remain in business
- listening with clear intent to the person and those in their support networks, showing empathy for their situation and clearly hearing their views on how they wish to be supported
- transparency and fairness in costs and charges for services, and how government funding and the consumer’s contribution is spent – quality includes value for money
- choice, flexibility and control
- a skilled, respectful workforce who are enabled to develop a continuous relationship with the consumer and carer to provide continuity and build trust
- respect for the diversity of consumers in all its forms, ensuring equal access to information and services for diverse groups
- efficiency, reliability and honesty in service delivery
- providing information that is clear and can be easily understood by a range of consumers, not bombarding people with information (e.g. 30 page agreements), speaking the consumer’s language and avoiding jargon and “bureaucratic speak”
- being supported to participate in community life, to make a contribution and to be as well and independent as possible
- showing respect for carers and informal supporters, their contribution and knowledge of the consumer, and their own needs to enable them to continue in caring roles
- being able to get a quality service without having to fight for it! The battles are exhausting.

**HOW DO CONSUMERS MEASURE WHETHER ONE SERVICE IS BETTER THAN ANOTHER?**

Our experience with HCPs tells us that currently consumers don’t know how to measure one service against another. When one consumer meets another, they often ask questions such as, “How much do you pay for your package each week?” or, “What percentage does your provider take for administration and case management?”

In the first instance, consumers want to feel that they are involved with a provider who is perceived to be acting fiscally fairly towards their consumers, rather than feel that the consumer is a, “cash cow to help make profits for their provider” (actual quote). Consumers have told us that they want
to compare and rate providers in a public forum (often likened to TripAdvisor), whereby individuals can say what is important to them and how well their provider was able to meet those needs.

Secondly, consumers want to measure the quality of providers by things like:

- can they choose their direct service providers?
- can they participate in decision making, both at a personal level and an organisational level?
- does the provider provide information in an understandable format?

Currently, comparisons for HCPs are only really possible by contacting the service and gathering information. Aged Care Assessment Teams/Services may be able to provide some information. Websites are used but only by a small proportion of consumers, more by families. Consumers and families would like to see information about pricing on the provider’s website. Word of mouth about services is an important source of information and is perceived to be more authentic and less biased.

**WHAT ASPECTS OF QUALITY CARE ARE ESSENTIAL AND SHOULD NEVER BE COMPROMISED?**

Aged care providers cannot escape their obligation to deliver services with due care and skill, regardless of consumer choice and control. However, there is also a need for a positive risk-taking approach where consumers can make informed choices about taking particular risks, but are also protected by appropriate safeguards.

Staff should have skills to do the tasks required of them, in accordance with the relevant code of ethics and conduct. Treating people with dignity and respect and as an equal partner in the support relationship is at the heart of quality care and should never be compromised.

Information provision is a key driver towards quality care outcomes. Consumers need to know what they are entitled to and what the parameters of the service are. For example, understanding how their funds can support their goals, what is specifically excluded, what opportunities there are to be creative in meeting needs and whether they can choose other services outside of the Approved Provider to deliver their supports are all necessary bits of information consumers need to make the right decisions for themselves, thus resulting in quality care.

Consumer *preferences* for service delivery, in particular for personal and intimate care related tasks, should never be compromised.

**HOW CAN QUALITY BE ACHIEVED ACROSS THE CONTINUUM OF AGED CARE SERVICES?**

Quality care and support in any context should be based on positive relationships and respectful partnerships, where decisions are made jointly based on clear information and good communication. A positive relationship will engender trust, where difficult issues can be discussed freely and joint decisions made that respect the consumer’s choices and the needs of their informal support networks.
The use of language in aged care services is a critical aspect of quality in many respects, which often conveys underlying attitudes about the older person. The language used needs to:

- be “person first” – conveying the positive identity of the person as a citizen with a unique identity and right to receive appropriate supports, not labels related to their condition
- convey that the consumer is in charge
- connect with the consumer’s life experience, not use jargon and acronyms
- make a real commitment to being in the person’s court.

While choice, control and flexibility might be harder to achieve within a residential setting, these are important aspects of quality to aspire to in any setting. A key aspect of this is to ensure that front line staff have accurate information and the knowledge and authority to respond flexibly to consumer requests, understanding both the limits and possibilities to be flexible and creative in response to consumer needs at the time. Provision of care and services needs to be timely and in accordance with consumer needs and preferences. Consumer preferences regarding their care workers should be considered and delivered upon (for example in relation to gender, cultural background, language).

Transparency and fairness are important to consumers who wish to know that the contributions made by government and consumers are being used most efficiently to provide the best possible support for consumers, and not to shore up the profits or assets of the provider.

Consumers object to the length and complexity of assessments, and the need to repeat their stories, despite recent changes to the aged care system designed to minimise this. Assessments need to be useful and meaningful to the person and lead to improved care and quality of life outcomes. The planning process also needs to include planning for future events (proactive care and well-being planning) as well as the strategies that enable the consumer to live an independent and autonomous life as much as possible. Respect for people’s wishes as expressed in an Advance Care Directive or via a substitute decision maker is also important.

Some providers have engaged in a process of co-production or co-design with consumers to develop their service models, such as with the transition to CDC. Consumers have the opportunity to not only be consulted or surveyed, but to actually participate in the design process alongside staff and managers of the service.

**WHAT ATTRIBUTES AND BEHAVIOURS DO CONSUMERS EXPECT FROM STAFF PROVIDING CARE?**

Fundamentally, staff need to have respect for consumers and the ability to communicate and engage in positive relationships that reflect such respect. Respectful behaviours include taking people seriously, being responsive to their needs, using common sense, treating people as adults (not infantilising people) and being able to communicate clearly. A respect for diversity is crucial, where consumer preferences are not judged based on the values and beliefs of the staff member. Different skills are required for different roles. Staff need to be competent at their roles which will inevitably require a level of training relevant to the role. However, recruitment based on values and attitudes is crucial, with other skills are able to be learned on the job. Consumers need to be able to
exercise some choice about the staff who support them, recognising the workforce constraints of the provider.

**WHAT IS THE GREATEST CHALLENGE FOR SERVICE PROVIDERS IN ACHIEVING QUALITY?**

Consumers comment frequently on the continued power imbalance between consumers and providers. Aged care is a complex system and consumers and carers feel that they do not have sufficient information to assert their rights. The frailty and vulnerability of some consumers will mean that they will simply accept what is offered and feel that they must be grateful for what they can get. They fear recrimination if they complain and while the system is “rationed” they do not have the right to a service to meet their assessed need.

Consumers also experience discriminatory attitudes towards older people, whereby people assume that the consumers cannot make choices or take control in arranging their supports, or delegate such control to a trusted representative.

Achieving a culture of quality throughout the organisation is also a challenge, where complaints are used to identify improvements rather than to blame staff or consumers for being “difficult”. This requires positive leadership at all levels of the organisation.

The existence of quality outcomes for all consumers should not be assumed purely based upon a provider’s favourable quality review by the Quality Agency. A standardised measure of assessing the true impact of a provider’s systems and practices on consumer lives needs to be carefully considered. There is also a misguided view that quality equals funding and that improvements cannot be made at low cost or no cost, by listening to what consumers want and being creative in meeting those needs and preferences. Spending may need to be re-prioritised in a constrained funding environment and consumers can be involved in help to determine those priorities. Quality is also about the nature of relationship and mutual respect that do not have a cost attached to them.

Providers will need to balance managing quality and returning a profit in a deregulated aged care system. The recent KPMG evaluation of CDC noted that some service providers may “cherry pick” the consumers who have lower levels of need.¹⁹

Providers will also need to balance the risk management culture present at some levels of their organisation with the ability to support and promote consumers’ right to take risks.

Providers may have the challenge of agreeing to negotiate individual arrangements with some consumers who request it. Many providers are worried about “opening the floodgates” if they are seen to be providing concessions to some consumers.

Providers can be reluctant to ask their consumers to participate in, and contribute to, the development and review of their service model. This will be an important tool for providers in ensuring their services are relevant in a competitive market. Consumer input can help to achieve efficiencies along the way, as there may be fewer issues that arise than if the service model is simply imposed on consumers.

There is a challenge for providers to accept when they have acted in a contrary manner and take steps to humbly rectify the situation, and acknowledge that sometimes the consumer may have shown them a better way to do things.
Ultimately, a consumer directed future in aged care services requires a mindset shift, reflected in the following quote:

“So the paradigm shift we are beginning to see is from a situation where providers manage their consumers to one where consumers, if they so wish, manage their own affairs and as a consequence, providers are becoming the clients of the consumers.”

Ron (consumer and carer advocate)

ENDNOTES


ii Department of Social Services, Formative Evaluation of the Home Care Packages Programme, Detailed Findings Report, April 2015. KPMG.

iii In 2011/12 the then Minister for Ageing went out to speak with older people about the Productivity Commission recommendations released in 2011. 31 conversations were held with 3,400 people attending. They also analysed 85 submissions from consumers to the PC about the future of aged care. These views were summarised in the article “What do Older Australians Want” by Dow et al., Australasian Journal on Ageing, Vol 32, No. 4, December 2013.

iv Department of Social Services, Formative Evaluation of the Home Care Packages Programme, Detailed Findings Report, April 2015. KPMG.