

**Western Linkages Consumer Engagement Forum
Consumer Directed Care – What will it Mean for Me?
Report Nov 2011**

The Western Linkages Regional Forum, Consumer Directed Care – What will it Mean for Me? was developed by the Western Linkages Consumer Engagement Task Group during 2011. The Forum sought to showcase the current ways that services in the West are utilizing Consumer Directed Care (CDC) principles to increase flexibility and maximize Consumer Control. The forum also sought to maintain a Dementia focus within the presentations including Service Providers whose consumer directed care packages include participants with Dementia and their Carers. The title was chosen to be reflective of the inclusiveness of the Service Provider and the Consumer / Carer perspectives throughout the program. Eighty four people attended the forum. Of these 76% were service providers and 24% were Carers / Consumers.

Marilyn O'Connor, Resthaven, provided an overview of Consumer Directed Care and teased out the differences between Person Centered Care, Consumer Directed Care and Self Directed Care. The continuum of control was discussed with reference to the level of consumer direction involved. International models were cited as a backdrop to the trials being conducted in SA and in the Western Region.

Resthaven also gave an overview of their In House trial of CDC which is underway in the West until June 2012. This includes over 20 clients who are in receipt of low care, high care and high care Dementia services. The need to review policies and rethink the position of a consumer not as a 'passive service recipient' was highlighted as a foundation of CDC to empower clients. A further important facet of Consumer Directed Care promoted was the need to remove the jargon from service provider language to avoid alienating consumers with acronyms. Importantly the issue was raised around the language we use to describe services i.e. care workers and whether we need to look at less segregated language to promote optimal relationships.

Cathy Lock, Consumer Participation Consultant, Domiciliary Care provided a presentation developed by Consumers to raise the concerns about Consumer Directed Care from a Consumer / Carer perspective. These included; managing quality, duty of care to the workers, possible tension between the client and the Carer regarding choices, auditing and accountability. This presentation provided subsequent speakers with an opportunity to showcase how the current models have responded to these constraints and concerns. A further opportunity to address these issues was provided by the Panel Session for questions at the end of the forum.

Ivy Diegmann, ACH Group provided an overview of CDC services within the organization. The presentation spoke on the evolution of this service model and the review of the policies and practices that is necessary to get decision making back into people's own homes and hands and out of the office. Innovation in the use of funds was illustrated

including gym memberships and the purchase of a GPS to facilitate independent transport to social outings rather than the traditional 'social support' service response. CDC was emphasized as being one piece of the 'puzzle' of support available to the person.

Jemima Lambell, Uniting Care Wesley and Virginia Meadows, CDC participant provided a presentation on Consumer Directed Respite Care from both a Consumer and a Service Provider perspective. This model is funded with the intention to address issues of flexibility and support to Carers, enhancing their quality of life and that of the person being cared for. Consumer Directed Respite Care can be used for a myriad of purposes including; personal care, in home services, a holiday, home modification and in home respite. It is underpinned by flexibility and consumer choice. The Consumer presentation from Virginia Meadows highlighted the experience utilizing CDRC from a Carer perspective. Consumer Directed Respite Care enabled her to return part time to work to 'recharge' in her professional environment. This was her personal choice in the creative use of Respite. Virginia also spoke of the issues around dealing with finite financial resources and the difficulty when the package funds were exhausted.

Sue Gould, Disability, Ageing & Carers, gave a perspective from the experience of the Disability Sector in the phased approach to self managed funds. This is an innovative model that enables people to have funds paid into their own bank accounts. There has been a broad range across phase 1 in the profile of the participating consumers. They are aged from 8 years old upwards, balanced between both genders and include country as well as metropolitan residents. Payments can be received by the person, a guardian, a host organization or a financial intermediary. Phase 1 has needed to explore a breadth of issues to enable to project to go ahead including a class ruling to ensure that money paid is not classed as income for Tax purposes.

Facilitators assist the person in developing a service plan. There are guidelines regarding what the money can be utilized for. Monies must be expended on disability support and is not available for i.e. food or household bills. Quality Assurance measures are in place and service providers must be from an approved provider. There are some exceptions to this where consumers can choose from general businesses such as cleaning and gardening services. During phase 1 participants are not able to employ their own staff. 61 individuals are currently self managing their funds. 4 people have chosen a host organization however the majority are managing the financial arrangements themselves.

Valerie Sandlant, Resthaven rounded up the presentations with further insight into the operation of Consumer Directed Care now and into the future, through the Consumers Directing Consumer Directed Care Project, including the training that is being developed and implemented to support Consumer Directed Care. This was followed by a lunch time workshop and panel session with the presenters.

One of the key messages from the day was the need for cultural change amongst service providers to support the implementation of Consumer Directed Care and the benefits of heightened control in terms of consumer satisfaction and raising self esteem. The need for more education for service providers and more information for Consumers to enable them to make informed choices was also highlighted. The models showed that despite the misgivings CDC can be undertaken successfully. Confidence in the concept of Consumer Directed Care was inspired by the models on show and the adaptability of participants to utilize their increased opportunities for control to best advantage.

Evaluation Feedback

The majority of participants reported that the Forum increased their understanding of Consumer Directed Care with 60% reporting they had learnt a lot from the day. A majority also reported an increase in their knowledge of models of CDC, the requirements for an agency to implement CDC and issues that are important to Consumers and Carers. Participants reported enjoying the presentation topics with 68% saying there was a great range. The catering and choice of venue at the City of Charles Sturt both also rated highly.

Participants were also asked whether they feel there are enough information resources available on CDC. They were also asked for suggestions regarding any further resources that could be developed. A large number of participants felt that either there are not enough information resources currently available (46%) or were unsure (30%). 20% said they believe there is currently enough information.

Participants suggested additional information could be made available such as a simple single A4 sheet of CDC information or condensed fact sheets. Participants noted that large amounts of information can lead to confusion. A simple pathway or flowchart for Consumers to access CDC was suggested. Information in a variety of media was also emphasized to enhance accessibility.

A CDC Helpline 1300 number was also proposed. It was further suggested that this could be a source of objective information about CDC and the differences between the models and providers. Information on the full range of available options was seen as important in empowering people to choose.

Participants also suggested that a DVD with interviews with Consumers to share their experiences could be developed.

Other suggestions included a simple template for budgeting and accessible information for service coordinators to enable them to assist potential clients to navigate through the service options. It was further suggested that there needs to be a promotion of the existence of CDC as an option. One Carer commented that; 'Before today I had no knowledge of CDC. Now I will be on the lookout'

The program included a Panel session comprised of forum presenters from Resthaven, ACH Group, Uniting Care Wesley Bowden and Disability Ageing & Carers. This was also

rated well by participants with the majority finding it either very useful (46%) or reasonably useful (50%).

Suggestions for future forums included an update on the HACC Innovative Ideas Funded Projects, (this is planned by Disability, Ageing & Carers for June 2012). Further topics around CDC options people with younger onset Dementia were also suggested. Other ideas included showcasing CALD services utilizing CDC, respite options and more around the various models of CDC available. The presentations from the Consumer perspective were well received and it was suggested that this could be further built on at future forums. A suggestion from the workshop (see report below) was that Forums could be utilised to support staff training by sharing positive stories of Consumer Directed Care and showcasing how practice has changed from previous service models.

Feedback from the Workshop

Feedback was sought on a series of questions during the lunch-time workshop. The questions were developed with Valerie Sandlant from the HACC Innovative Ideas Funding 'Alternative Models' workgroup. The intention was for information gathered from the workshop to be made available to the workgroup to further inform the development of the Innovative Ideas Consumer Directed Care projects. 54% of participants rated the workshop as very useful and 46% said it was reasonably useful with new information generated.

Question 1: What are the positives and negatives about Consumer Directed Care?

Question 2: What do Consumers need to enable them to direct their own care?

Question 3: What do service providers need to do to enable consumers to direct their own care?

Question 4: What training would staff need to participate in Consumer Directed Care?

The workshop generated lively discussion between Consumers / Carers and service providers. The following themes were highlighted by the groups;

Question 1: What are the positives and negatives about Consumer Directed Care?

Positive:

The shift in the service provider 'mind set' was highlighted as reversing the power and control balance and moving away from the notion of the client as the passive receiver of services. Choice and control were emphasized as a positive aspects underpinning the model leading to Consumer empowerment.

Flexibility was also highlighted as providing more tailored/ individualized services and creating time lines without boundaries. This was emphasized as being particularly beneficial for working Carers. The increased self esteem and confidence experienced by participating Consumers through enhanced independence was also raised.

The transparency of the budget and service provision was also seen as a positive as was the safeguard of the service provider retaining a facilitating role to assist the client and provide advocacy with dispute resolution. Participants also felt that potential cost saving could result in an overall increase in services.

Negative

Managing quality emerged as a concern for participants in guaranteeing the quality of workers. A concern was also raised regarding OHS&W issues for workers and the expectations placed upon them. Additional responsibilities for service providers such as audits, meetings with contractors, police checks, time spent supporting clients to utilize the model and administration work were also highlighted. It was suggested that the cost of services may rise as a result of this.

It was suggested that different providers with different interpretations of CDC may lead to inconsistency. A further concern was raised around Consumers not choosing services that are most needed and expending the funds on other priorities. The question was raised regarding what safety net would be in place for this contingency.

Budgeting skills and the time and inclination to manage the financial arrangements were cited as a negative. It was highlighted that Consumers would need additional resources and training to manage this. It was noted that additional administrative work could mean an unwanted additional responsibilities for the Carer.

Workforce issues were also cited in terms of competition for high quality care workers. The additional resourcing required to train Consumers and service providers to utilize CDC was also raised.

It was suggested that the radical change represented by CDC could lead to confusion and that the amount of information may be overwhelming to potential participants. Capacity issues around decision making and potential family conflict regarding needs were also raised. Participants noted also that the CDC system still creates rules and complete flexibility is not achieved. Potential difficulties in successfully marketing CDC were also highlighted.

Question 2: What do Consumers need to enable them to direct their own care?

Training for Consumers was highlighted as fundamental to the success of the model. Participants suggested that Consumers would require training in computer literacy and information and education on the options available and how CDC works. Forums and peer support opportunities to hear the stories from other Consumers were suggested. It was emphasized that service providers need to operate from a 'keep it simple' perspective to avoid an overwhelming amount of information for Consumers. Specific education on budgeting and a budgeting template were proposed. It was emphasized that all information and training should be provided in a variety of mediums i.e. on line, paper, over the phone and it was highlighted that this should be provided more than once and with follow up. It was suggested that Consumers need transparency in order to monitor where the money goes.

Good communication was also emphasized as fundamental to the success of the model. Access to a ready help phone number was suggested. Clear guidelines were emphasized with suggestions around a catalogue of services including costs and clear rights and responsibilities documentation. A clear pathway to services was also suggested including a single point of entry to CDC.

Better coordination between the consumer and the coordinator was also seen as paramount as was the development of a trusting relationship with a facilitator to empower the Consumer to take control. Encouragement from the services provider was also raised to assist in empowering Consumers by raising their self belief in managing the model. Working at the client's pace and ensuring they have adequate time to understand the process was raised.

CALD specific information and culturally appropriate services through CDC were also highlighted. Further suggestions included the need for the model and associated information to be jargon free, less assessment over the phone and embracing the understanding that each person's situation is unique.

Question 3 : What do service providers need to do to enable Consumers to direct their own care?

An innovative approach and change in service provider orientation and flexibility was seen as paramount. It was suggested that service providers must engage in a new way of thinking and relinquish control. True openness and creativity were also emphasized as was promoting positive images of older people and their strengths and goals. It was proposed that staff resistance to change needs to be addressed. Staff education and training were raised (see question 4). Information and understanding of available models of CDC and CDC within their own organization was highlighted. The provision of ICT tools and training for Consumers were also suggested. Clear, concise information in a variety of accessible mediums was highlighted.

Good communication and support and assistance for the Consumer to navigate the system were also raised. Importantly the issue was raised around the language we use to describe services i.e. care workers and whether we need to look at less segregated language to promote optimal relationships. Building the relationship with a strong foundation of understanding the person was also emphasized and supporting the person to develop the way that they can best utilize the CDC model.

Creativity and innovation were also seen as fundamental to ensuring true flexibility. Practical support for the Consumer to manage the administration was also highlighted. Ensuring quality assurance processes are in place was also raised. It was also suggested that the current reporting and administrative requirements need to be simplified as they are currently quite demanding.

A single point of entry for CDC services was proposed to support freedom of service provider choice. Support and assistance with legal and financial implications and processes were suggested.

It was proposed that the principles of CDC need to permeate throughout the entire organization to assist in the service embracing the philosophy.

Question 4: What training would staff need to participate in Consumer Directed Care?

It was suggested that training should be intensive to start then moving to regular in service training, supported by fortnightly team meetings and weekly debriefing sessions. Coaching and mentoring mechanisms were also suggested, as was person centered Better Practice Project 'Right Relationship' training. Training should include communication, both verbal and non verbal. Training in the tools to assist Consumers to direct their own care was also suggested such as processes to enable them to identify their own priorities for service based on needs.

Training to support a cultural shift in the service provider mind set was also emphasized that includes working with the client to avoid 'taking over' and the values and attitudes to empower Consumers. Forums were suggested to support training and the inclusion of training of service providers by Consumers was also proposed. It was further proposed that a Forum could be utilized to share positive and innovative stories of Consumer Directed Care. Practical examples could be followed up with the theory, i.e. How has practice changed? It was suggested that training needs to tease out the differences between Person Centered Care and Consumer Directed Care.

Training around advocacy to assist in dealing with disputes was also recommended. Practical training in managing budgets and accounting was also suggested. Training in managing quality assurance processes and managing change were also proposed. Skills in early intervention to recognize where CDC is not working optimally were also seen as important as was the ability to recognize elder abuse and take appropriate action. Evaluation methodologies were suggested as part of the training.

Communication skills included the replacement of jargon and acronyms with more 'user friendly' language. Further training on what is available to clients and assisting them to navigate was also suggested.

Cultural awareness was further highlighted as an important facet of the training. There was a quote that 'every person is different; staff need training to understand and value the differences'.

Western Linkages would like to extend special thanks to the Consumers and service providers from the Consumer Engagement Task Group and the large number of organizations across the Western Region who provided presentations, displays and support on the day. Thanks are also extended to the City of Charles Sturt for their generosity in hosting the event.