Consumer Directed Care (CDC)

Henry Brodaty
2012

• Minister Mark Butler & Prime Minister Gillett announced $3.7b aged care reform package
  *Living Longer Living Better*

• Overseen by Aged Care Reform Implementation Council, chair Peter Shergold
Policy

• *Living Longer, Living Better* reforms
• From Aug 2013, Home Care Packages Program replaced former care packages (CACPS, EACH, EACH-D)
  – Aug 2013: All new packages required to be delivered as CDC
  – July 2015: All packages will be CDC

Dep Health & Ageing: *Home Care Packages Program Guidelines*, Aug 2013
Policy

• “CDC is 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 and services they access and the delivery of those services, including who will deliver the services and when.”

Dep Health & Ageing: *Home Care Packages Program Guidelines*, Aug 2013
What is expected in CDC?

- Care planning should set goals & be consumer driven
  - Choice, control
  - Support decision making
  - Responsive to customs, beliefs, backgrounds
  - Wellness & re-ablement
  - Maintenance of independence

Dep Health & Ageing: *Home Care Packages Program Guidelines*, Aug 2013
How much consumer control?

• Range of options for consumer management of package
  – May vary over time

• Examples
  – Making contact with service providers, negotiating fees, record keeping, managing invoices
Which services?

- Services should support consumer’s goals
- “[Under CDC]…the consumer should not be limited by a “standard” menu of services or service providers” (p32)
  - Encouraged to be innovative
  - Could use sub-contracted services
- “Regardless of how services are delivered and by whom, the home care provider remains responsible for service quality and meeting all regulatory responsibilities.” (p34)

Dep Health & Ageing: *Home Care Packages Program Guidelines*, Aug 2013
Different models

Consumer holds budget
Select from prescribed menu
Select any service, few restrictions

Provider holds budget
Select from prescribed menu
Select any service, few restrictions
Individualised Budget

- Home care *provider* is the budget holder
- Consumer provided with monthly statement
- Should clearly state available amount & planned expenses
  - Admin costs
  - Advisory/management
  - Service/support provision
  - Contingency (optional, no more than 10%)

Dep Health & Ageing: *Home Care Packages Program Guidelines*, Aug 2013
Individualised Budget

• There is a common list of care/services for each Home Care Package (& exclusions)

• Home care package by level
  – Level 1 $20.55/day ($7,501/yr)
  – Level 2 $37.38/day ($13,644/yr)
  – Level 3 $82.20/day ($30,003/yr)
  – Level 4 $124.95/day ($45,607/yr)

Dep Health & Ageing: *Home Care Packages Program Guidelines*, Aug 2013
Policy – flexibility for consumers

- the consumer has ownership of decision-making
- the consumer is encouraged to identify goals, – basis of Home Care Agreement and care plan with the assessed care need;
- the consumer decides level of involvement in managing their package
- the consumer is able to exercise choice in the way that services are offered and delivered
Policy - exclusions

- ‘Cashed out’ or paid directly to consumer
- General income
- Food (except enteral feeding)
- Permanent accommodation, (eg mortgage, rent)
- Home care fees
- Other types of care funded by government
- Home modifications not related to care needs
- Travel, etc for holidays
- Entertainment activities
- Items covered by Medicare Benefits Schedule or Pharmaceutical Benefits Scheme
- Gambling activities
- Illegal activities
The concept

• CDC can increase consumer choice
  – Consumers will have access to information on health costs & quality
  – Can tailor what they receive
• CDCs need to recognise:
  – Capability - vulnerability
  – Information – what’s needed/ what options?
  – Choice – can they switch provider or service

CDC can control costs

- Enhance consumer awareness of health costs
- Fixed funding & cost sharing under CDC make consumers more sensitive to costs
- People spend their own money more carefully than other people’s money
- Control is switched from provider to consumer
  – Kerbs unlimited demands?

Advantages of CDC

- Choice
- Flexibility
- Empowerment
- Autonomy vs Beneficence vs Justice
Disadvantages of CDC

- Hassle
- Onus, responsibility
- Uncertain of options
- Deciding on who is the beneficiary
- Justice – disadvantaged populations gaining equal access
Buying a TV

- Do I want a smart TV, inbuilt DVD player, an LCD, LED, plasma or 1080p?
- What do I need?
- How big?
- How much?
- What choices?
- & if only 1 shop in town?

LF Low The Conversation 9 August 2013
For providers: the devil is in the detail

- Informing consumer about options?
- Choose services or goals?
- Financial model – costs for providers to set up services
- Who keeps records?
- CDC for older people - differences
For providers: the devil is in the detail

- Provider is paid for services
- If client on books dies/admitted, provider pays for staff but is not paid because no service delivery
- Have to fit services to client
  - Schedule
  - Not in house provider
- Hoarding of hours
- Lack of flexibility
For consumers?

• Whose is consumer?
• Whose needs?
  – Older Person
  – Family member
• If older person cannot decide how well can carer judge?
• What if provider does not let you know what is possible?
• What if choices are limited?
Perceptions of values: caregivers and people with dementia

- 266 dyads of person with mild/mod dementia (PWD) and family caregiver (CG)
- 5 care related values – autonomy, burden, control, family & safety
- CGs underestimated PWD’s values in all areas
- Main differences were related to CGs perceptions of the PWDs involvement in those decisions
  - If PWD weren’t involved, values were less emphasised

Perceptions of values: change over time

- CGs perceived importance of PWDs’ values measured by the Values & Preferences Scale
  - 37 items; 3-point scale, 1 (not at all imp), 3 (very important)
  - M = 86.8 (SD = 12.9; range 48-110)
- Perceived importance of PWDs’ values significantly decreased over time (2.76 points/yr)
- CG beliefs about care, PWDs’ self report baseline values & family relationship impacted on this

Perceptions of values: change with type of decision

• 10 triads of PWD, family CG, professional carer
• Variability in how PWD was involved in decisions
• PWD had more autonomy in decisions about daily activities, but less about medical treatments or moving to RACFs
• Non-involvement in decisions was due to PWD no longer being capable, no choices available, or PWD not given the opportunity to participate

Involving PWD in decision making

- Optimal involvement facilitated by
  - Thinking of PWD as capable
  - Assessing decision-specific competence
  - Clarifying values
  - Understanding relationships & context that might limit PWD’s involvement

Buying Care

• Setting goals vs offering menu of services?
• What is available?
• Who holds the budget?
• How does government ensure money well spent?
• What is experience overseas?
• What’s happening in Australia?
Buying Care

- The Home Care Standards against which community-care providers are reviewed and accredited have not been changed in response to CDC.
- No safeguards to ensure that service providers give customers a wider range of choices and information about possible repercussions of choices.
Knowing what you need

• Patient to doctor
• Can you give me something for my headache?
• Prescribe analgesic? OR
• Diagnose high blood pressure
• Prescribe BP tablets?
• Advise about exercise, weight control, diet, etc?
Buying Care

• Customer satisfaction reflects relationship more than service quality
  • Giving them ‘what they want’ may make them happy but not enable them to live more independently
  • CDC ≠ enablement
Barriers

- Resistance to self-direction from service providers & policy makers
  - Need to find balance between protecting vulnerable & restricting those who are capable of self-direction
- Limited support to facilitate consumer voice & choice in family decision making
- Lack of advocacy for CD by older adults

Barriers to PWD in decision making

- Professionals or CGs controlling agenda
- Family dynamics
- Culture of care that doesn’t prioritise PWD’s involvement in decisions

Experience in other countries

- UK
- USA – Cash and counseling for Medicaid

- Ottman G et al, 2013
- Low LF et al, 2011
Experience in other countries

• Cash & Counselling demonstration (USA) (disability, not just old age) (1998-2001)
• 6-8% of eligible people signed up
  – Variability in elderly sign-up (vs adult non-elderly)
• Most common reasons for participation
  – Greater control on hiring CGs, paying family members/friends, more convenient times, better care

Budget holding vs not

- **Cash & Counselling Demonstration (USA)**
  - 10-20% allowance in cash to spend on incidentals
  - Remainder managed by bookkeeping service

- **Individual Budgets Pilot (UK)**
  - Choice of how to receive allowance
  - 55% payment
  - 33% managed by agent, local authority

Low LF et al. Australasian Journal on Ageing. 2012: 31(1); 47–51
Experience in other countries

- Systematic review
- Older people want greater involvement in care decision making
  - Flexibility in spending
  - Control in employing care workers
- Older people see CDC differently to younger people
  - Systems designed for younger people with disabilities may not be appropriate
- CDC preferences shaped by self-confidence, skills & health status

Experience in other countries: USA

- Wide variation in state by state implementation
  - May be reason for mixed results in satisfaction
  - E.g. California (minimal support)
    - Lower satisfaction & preference for CDC amongst older adults
      - Where support/training available, higher interest amongst older adults
    - Good satisfaction for CGs

Experience in other countries: UK

- UK – individual budgets
- Types of participants
  - Passive (want care to stay the same)
  - Anxious (some benefit, see admin as burden)
  - Those with experience in admin, social care who embraced programme
- Carers expressed better satisfaction if they were more involved in care planning
- Evidence that older people need more support for successful CDC outcomes

Experience in other countries

• Take up rate is low
• Hitches
  – People without advocates
  – Financial exploitation
  – Bookkeeping
• What is the evidence of effectiveness?
Experience in other countries

• Reasons for not participating
  – Already satisfied with care
  – Concern monthly allowance was not sufficient to cover costs
  – Concerns about administrative burden
    • Hiring/firing workers
    • Payroll tax
    • Tracking expenses

Experience in other countries

- Reasons for enrolment difficulties
  - Resistance from service providers
  - Lose market share, workers
  - Preconceptions about capacity of elderly
  - Outreach workers explaining CDC were also case managers & believed clients were too frail, sick or too limited to participate
  - Outreach workers’ time
  - Language diversity

What is happening in Australia?
Policy

• 7,000 Home Care Packages delivered CDC
  – Includes 1,000 from pilot study
• Expected 60,000 existing packages converted to CDC by July 2015
  – Can convert earlier if provider is ready
Capacity building

• Council on the Ageing Capacity Building Projects

• Two capacity building projects have been funded to support the introduction of Consumer Directed Care. Consumer Directed Care

Capacity Building Service

• Council on the Ageing (COTA) is partnering with Aged and Community Services Australia and Leading Aged Services Australia to equip providers to deliver quality consumer directed services in home care.
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Dep Health & Ageing: *Home Care Packages Program Guidelines*, Aug 2013
What has been done so far - pilot

- 1,000 CDC packages (2010-12)
- Evaluation conducted less than 12 months after start of program
- CDCH – consumer directed high care
- CDCHD – consumer directed high care, dementia
- CDCL – consumer directed low care
- CDRC – consumer directed respite

Breakdown of CDC package expenditure

Proportion of CDC package: in-house vs brokered

## Top 5 accessed support by % participants

<table>
<thead>
<tr>
<th>CDCL</th>
<th>% part</th>
<th>CDCH</th>
<th>% part</th>
<th>CDCHD</th>
<th>% part</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domestic assistance</td>
<td>64%</td>
<td>Activities of daily living</td>
<td>75%</td>
<td>Activities of daily living</td>
<td>52%</td>
</tr>
<tr>
<td>Activities of daily living</td>
<td>45%</td>
<td>Domestic assistance</td>
<td>52%</td>
<td>Domestic assistance</td>
<td>22%</td>
</tr>
<tr>
<td>Social support</td>
<td>30%</td>
<td>Social support</td>
<td>39%</td>
<td>Nursing care</td>
<td>22%</td>
</tr>
<tr>
<td>Nutrition, hydration and meal preparation</td>
<td>23%</td>
<td>Nursing care</td>
<td>31%</td>
<td>Social support</td>
<td>20%</td>
</tr>
<tr>
<td>Emotional support</td>
<td>18%</td>
<td>Nutrition, hydration and meal preparation</td>
<td>29%</td>
<td>Clinical care</td>
<td>20%</td>
</tr>
</tbody>
</table>

Excludes administration and care planning and management

Source: 2<sup>nd</sup> CDC provider data collection (July-Sept 2011)

# Reasons for participating in CDC by package care history

<table>
<thead>
<tr>
<th>Reason</th>
<th>Received packaged care before</th>
<th>Had not received packaged care before</th>
</tr>
</thead>
<tbody>
<tr>
<td>I wanted to have more choice of which services I used</td>
<td>41%</td>
<td>30%</td>
</tr>
<tr>
<td>I wanted to have more choice of providers</td>
<td>16%</td>
<td>18%</td>
</tr>
<tr>
<td>I wanted to have more control over my care planning</td>
<td>46%</td>
<td>34%</td>
</tr>
<tr>
<td>It was recommended by my care provider</td>
<td>70%</td>
<td>75%</td>
</tr>
<tr>
<td>I was not satisfied with my previous community care</td>
<td>11%</td>
<td>2%</td>
</tr>
</tbody>
</table>

“I felt included in care planning”


![Pie charts comparing CDCL and CACP responses](chart.png)
“I felt included in care planning”

Satisfaction compared to 6mths ago

CDCL

CACP

Satisfaction compared to 6mths ago

Examples of innovative uses of CDC package funds

• “CDC participant with mobility limitations purchased a shower stool & arranged for bathroom modifications to enable her to shower herself independently rather than rely on daily personal care.”

• “CDCL participant used his package to purchase a light weight vacuum cleaner so he could clean his flat himself, rather than using his package for domestic assistance”

Examples of innovative uses of CDC package funds

• Northern NSW older woman, ↓ mobility, cognitively intact, loved garden
• Used package for
  – transport, instead of her ringing provider, she had open tab with local taxi company
  – Gardener – whom she sacked/ replaced
• Monthly profit and loss statements

Sally Yule, HammondCare
Evaluation findings

• Few participants fully self-managed their package
• CDCH & CDCHD participants & their carers were more actively involved in decision-making than CDCL
• Participants chose similar types of services, but exercised control over how the services were delivered

Evaluation findings

- Appeared to have a positive effect on satisfaction
- Conflict between consumer choice and service provider’s responsibility/duty of care to ensure appropriate support
- Cost-effectiveness unclear
Issues for service providers

• Reasons for participating in the pilot CDC
  – Already using PCC
  – Expected demand
  – Opportunity to do things differently

• Criticisms/difficulties
  – Flexibility was good, but still needed direction on following guidelines
  – Ongoing support was lacking
  • “the Department just gave us the guidelines & the dollars and said ‘off you go’.”

Issues for service providers

- Developing their own approach
  - How it would work in practice
  - Suitable participants, working with stakeholders (ACAT) and brokered services, participant agreements

- Suitable staff and staff development
  - Usually used their most experienced staff
  - Identified key skills required
  - Need to provide training for staff about CDC


Aged & Community Services Australia proposed slowing CDC roll out

Different view to COTA did not support this
• Too many choices?
  – What do you need to know before making a choice?
• In-built intractability
  – Standards for service providers have not been changed

CDC - conclusion

• It’s the future and it’s now
• Need adjustment from industry, service providers, consumers
• Potential benefits outweigh hassles

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• Thanks to ACRIC, Megan Heffernan, Lee-Fay Low and Sally Yule