PERSON-CENTRED CARE AND CONSUMER DIRECTED CARE CLARITY IN COMMUNICATION: DISCUSSION PAPER

Prepared for the Department of Health

Victorian Government

2014

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ACKNOWLEDGEMENTS

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EXECUTIVE SUMMARY

WHAT DID WE WANT TO KNOW?

Are person centered care (PCC) and consumer directed care (CDC) the same or different? If they are different, what are the differences?

WHY IS IT IMPORTANT?

PCC and CDC are central to Australian and state government health and aged care policies. Many organizations state that they are committed to both. Yet there remains confusion over exactly what the terms mean, they are used interchangeably and it is important if policy is to translate into practice that all stakeholders have a common definition and use the terms consistently.

WHAT STRATEGIES WERE USED?

The international literature on PCC and CDC definitions was reviewed and synthesized;

Similarities and differences were identified as was the historical development.

Although not the primary purpose of this review, where potential perverse outcomes were identified these were noted.

A draft paper was developed and sent to local and international experts for critical comment and suggestions.

The paper was revised taking account of feedback.

The second draft was considered by the Victorian Department of Human Services Quality Improvement Unit and the Quality in Public Sector Residential Aged Care Reference Group (comprising representatives of various departmental programs, aged care experts, academics, consumers, sector representatives, and other aged care stakeholders). Their feedback informed the final document.

WHAT WAS LEARNED?

PCC and CDC have a common history and philosophy. Both reflect a reaction to the long held philosophy that the mind and body were separate.

In the health care field mental health – or psychiatric illness – is still stigmatised and health care systems are generally organised around physical health with some acknowledgement of mental health.

The history of medicine has been one of éxperts' telling patients what is best for them and expecting unquestioning compliance. This paradigm is still very much in existence, although increasingly being challenged.

The human rights/ anti-authoritarian movements of the 1960's and since have supported the evolution from expert/patient toward partnerships in care and even the consumer/patient leading their own care.

Carl Rogers is generally considered the 'father' of person-centred approaches to care. Although his work concentrated on counselling, the principles have been developed and applied across the health disciplines and beyond – notably including education and leadership.

Most definitions of PCC focus on the consumer as 'the person', however there has been a gradual recognition that all stakeholders are people and thus should be included as persons in any PCC definition.

Some writers have argued against PCC as too individualistic and instead contended that interdependence and relationship-centred care should be the model.

Others have included relationships as part of the PCC definition.

Non-contentious to the definition are respect, equality, feeling worthwhile and having choice. Summarising the various definitions the following attributes were perceived as central to understanding PCC.

- Having a whole of organisation philosophy and approach to care and support

- Respecting and valuing each individual as unique

- Recognising the need of all people to have purpose and to feel they matter

- Providing unconditional positive regard

- Actively listening to the whole person in context

- Focusing on strengths and goals and working with in a positive framework

- Recognising the significance of a positive social environment

- Supporting rights, values and beliefs

- Recognising that all behaviour is meaningful

- Supporting positive relationships across all stakeholders

- Enabling choice wherever relevant to the person and within an environment of respect for others.

CDC aims to maximise the opportunity of choice: choice about what, when, how, and who delivers services.

Opportunity to choose requires service availability and accessibility and the capacity to buy those services.

Government funding traditionally has gone to service providers; increasingly in alignment with CDC policy, governments are experimenting with ways in which to directly or indirectly fund the consumer rather than the provider.

CDC in Australian aged care is based on the following *key principles:*

- *Integrated – CDC should be integrated into existing programs as an optional mode of care delivery and operate within the constraints of the current legislative arrangements.*

- *Responsive – CDC should be responsive to the changing needs and circumstances of care recipients and carers, and enable adjustment of budgets and services to meet those needs.*

- *Inclusive – CDC should take into account the needs of care recipients and their carers and consider its contribution to, or impact on, the social inclusion of care recipients and carers.*

- *Equitable – Care recipients with the same or similar needs and circumstances should receive comparable allocations of budgets and services.*

- *Optional – CDC should be offered to care recipients as a voluntary option.*

- *Care recipient and carer-centred – CDC should take into account the needs and views of care recipients and carers and support them having control and choice over their care.*

- *Supportive – Care recipients and carers and providers should be provided with a range of support to make informed decisions and practise CDC, including education and advocacy.*

- *Sustainable – CDC should provide an affordable, long term option for delivery of care for Government that meets the needs of care recipients and their carers* 2012: 2.

Even where the consumer receives funding subsidies CDC may be hampered because of barriers such as services not being available and accessible where and when required; or consumer literacy is poor. Education and advocacy are recommended to maximise informed choice.

Summing up, PCC and CDC have arisen from the same philosophical ground but they are not the same thing:

PCC is an all-encompassing, whole of organization approach to care and support services that maximises self-determination, choice, goal achievement, and well-being. Further the *person* is conceptualised as inescapably situated and thus capable of being known only through their continuous, ever-evolving experiences and relationships and their attributed meanings, values and beliefs.

CDC is the delivery of services whereby informed consumers are given the opportunity and supported to assess their own needs, determine how, when and by whom these needs should be met, and evaluate their services according to their own expectations. Consumers thus have greater control over their own lives and well-being.

Understanding the differences and using the terms consistently across policy, governance and practice will enhance communication and predictably ultimate care outcomes.

INTRODUCTION

Person-centred care and consumer directed care had the same embryonic beginnings but have developed quite separate meanings in Australia. Nevertheless, commonly the terms are used interchangeably, conflated and misunderstandings arise as a result. This paper aims to reduce the confusion and arrive at a shared understanding and usage for all stakeholders.

Aim is to reduce confusion and aid clarity

OBJECTIVE
The objective of this discussion paper is to inform quality in PSRACS by:

1. assisting the development of a shared understanding of PCC, and

2. assisting the development of a shared understanding of CDC.

METHOD
- A review and synthesis of the literature on PCC and CDC was undertaken.

- Similarities and differences were identified including:.

  - Origins

  - Historical development

  - Contemporary usage

- A draft paper was developed and sent to local and international experts for critical comment and suggestions.

- The paper was revised taking account of feedback.

- The second draft was considered by the Victorian Quality in Public Sector Residential Aged Care Reference group before being finalised.

A VERY 'POTTED' HISTORY

The origins of PCC can be seen in early philosophy that saw the mind and body as separate

We can go back at least to Plato [429–347] to see how we arrived at our current interest in person-centred and consumer directed care. Put very simply, Plato conceptualised humans as souls and bodies – perhaps the beginnings of 'dualism'or the mind/body split which has been primarily associated with the later works of René Descartes [1596-1650] (Rozemond 1998; Skirry 2006; Robinson 2012). This way of viewing humans has had a lasting impact on health disciplines, education, research, policy and practice. More importantly it has defined the heath care consumer experience for generations. Still today we see clear evidence of this dualism in the way that physical and mental illnesses are separated.

Physical illness is legitimate; mental illness and those who treat it suffer suspicion, lower credibility and stigma. Talcott Parson's (1951), significant in health sociology) wrote extensively and persuasively about what he defined as the 'sick role'. Essentially, for a sickness to be accepted by 'society' a person had to have that illness diagnosed (legitimated) by a medical doctor, give their body (and their clothes!) over to the health care professionals and comply with doctor's orders without questioning. In return for their compliance they were able to relinquish their normal responsibilities for the recovery period. The doctor was 'God'. The medical model of care focussed on the physical ailments and the tasks required to mend the body**.** The history of how mental illness was regarded and treated is peppered with stigma, restraints, lunatic asylums and all of the devastating experiences that occurred therein (Rosenhan 1973; Szasz 1960; Risse 1988; Chodoff 1982; Foerschner 2010).

Complementing the illness culture and medical model of disease management, nursing had a military and religious history which championed strict task efficiency alongside cleanliness being next to Godliness. Nurses and patients were expected to be non-questioning and obedient to the doctor's orders (Nay 1994).

Goffman (1967) wrote a highly significant book *Asylums* on the notion of 'total institutions'. He described how such places stripped inmates bare of their identities, by for example replacing personal clothes with uniforms (on admission to hospital a hospital gown was worn and the patient remained in bed); having strict routines (doctors' rounds, toilet and back rounds), depersonalising by the use of diseases and room numbers instead of names (such as referring to a person who had suffered a stroke as 'the stroke in room 107'), punishing an inmate for 'non-compliant' behaviour and generally organising the institution for the benefit of staff. Seligman (1975) introduced us to the notion of 'learned helplessness' whereby (extrapolating his work on dogs to humans) for example a person would learn to be helpless if/when all sense of control was taken from them and they had no choice in their lives. In aged care until relatively recent history this was the norm. In most cases the staff were well intentioned but were killing with kindness in an environment of 'benevolent oppression' (Nay, 1999). In such an environment

caring is equated with doing for, knowing what is best for you, … fostering dependency. Such caring is disempowering, infantilising and oppressing, all within a framework of kindness and benevolence (1999: 154).

Human rights and anti-authority movements led to mounting calls for patients to be partners in care and subsequently for consumer literacy

The sixties and baby boomers changed society as we knew it. Sociologists and psychologists focussed attention on marginalised groups and associated problems (eg. Becker 1963; Ryan 1971). Equality for all was championed and rights movements sprouted up everywhere: women's' rights, gay rights, black rights, indigenous, children's, ethnic, elder rights and of course consumer rights. Health care was no longer the domain of Western medicine but options arose from the East; 'natural medicines' became popular and enabled greater choice (Pirotta et al 2000; ABS 2008). Technology and the internet educated consumers about the myriad of choices and offered consumer literacy (and often misinformation). Resistance to authority in all forms, including the doctor, blossomed. The individual and 'self' became prominent and the view of an integrated, holistic 'person' challenged the mind/body split[1].

Complementary therapies are widely used as consumers and scientists recognise mind and body are NOT separate

There is ample evidence to demonstrate the many ways in which mind and body are mutually constituted (eg. Guowei, 2014; Baker 1994;Kort 1984;Heyne et al 2004; Trivedi 2004; Evans 2002; Better Health Channel Vic) Adverse impacts on the body can result in depression; depression can assault the immune system and result in further physical illness; positive attitude and physical exercise improve immune function and reduce pain; the environment in which people live, work or receive health care can influence health; music, having relevant information and feeling confident in a calm environment are associated with

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[1] Some would argue we have gone too far in the emphasis on the self and this has resulted in a rise in narcissism and a sense of entitlement (Twenge & Cambell 2013; Mackay, H 2013)

improved recovery rates, and noise, adverse aromas, intense lighting, crowding and chaos are associated with anxiety and reduced recovery rates (Baum et al 1981). The guru of stress, Seyle (1956) led generations of scientists to demonstrate how feeling out of control and stressed can adversely affect physical health.

Following particularly the philosopher Heidegger (1962) we have a recognition of the way in which people are situated always within 'Time' and their history (1962). Heidegger raised awareness of humans *Being* in the world and of the world. Understanding of the individual cannot be achieved by a simple focus on the individual out of context. We are inescapably embedded in our historical space and time. Any definition, therefore of the person/person-centredness ipso facto is inclusive of the situatedness.

Coming back to Seligman (2004), he turned his attention away from the abnormal and toward improving life for 'normals' and led a hugely successively 'movement' in positive psychology. He argues that happiness is not the ultimate human goal, rather well-being is:

What is it that enables you to cultivate your talents, to build deep, lasting relationships with others, to feel pleasure, and to contribute meaningfully to the world? In a word, what is it that allows you to flourish? "Well-being" takes the stage front and center, and Happiness (or Positive Emotion) becomes one of the five pillars of Positive Psychology, along with Engagement, Relationships, Meaning, and Accomplishment—or PERMA, the permanent building blocks for a life of profound fulfilment (Seligman 2004).

Within the leadership literature also we can see similar themes in the works of Goleman on emotional (2004) and social intelligence (2007) and Covey (2004) on leadership. In effect great leadership is person-centred and focussed on well-being. Policy and practice (or at least the contemporary rhetoric) have come a very long way from the dualism that made our health system what it was/still is: a medical model that depersonalised patients, focussed on diseases and tasks and took place in institutions organised for the benefit of staff!

And so we come to person-centred and client directed care.

PERSON-CENTRED CARE (PCC)

Rogers introduced client directed counselling whereby the counsellor was the expert dispensing advice to a compliant client and instead argued that the client is the expert and with unconditional positive regard, active listening and facilitation would make their own choices and take greater responsibility for their lives and health care.

Carl Rogers was and still is one of the most influential thinkers in psychology. His work can be seen informing most of the health sciences and education. He is the 'father' of person-centred care and its numerous expressions. Roger's work was termed client-centred counselling (1961). Rogers dismissed the typical counselling approach whereby the counsellor was the expert dispensing advice to a compliant client and instead argued that the client is the expert and with unconditional positive regard, active listening and facilitation would make their own choices and take greater responsibility for their lives and health care. This approach enabled the client to identify and achieve their own goals and maximise their strengths gaining a sense of achievement and a feeling of worth. This is unlike the medical model that may have left the health practitioner feeling good while the client learned helplessness. Rogers referred to the practitioner's role as being 'midwife to a new personality' (Rogers 2012). He argued that the relationship moved from one in which the expert had all the power to a partnership that was empowering for the client. Although the terminology varies, it is difficult to find a health/social science discipline that has not in some way embraced these ideas. Examples of terminology include: woman centred care, family centred care, student centred learning, patient centred care, consumer centred care and consumer directed care. Within this context, the latter term is synonymous with PCC and not the CDC which will be explained later in this Paper.

A key principle of PCC, according to McLeod (2003), is that person-centred practitioners 'seek to create a relationship with clients that is characterized by a high degree of respect, equality and authenticity.'(168). Important to authenticity is congruence. Rogers explained that congruence occurred when:

Respect, equality, authenticity, congruence and being genuinely connected are central to PCC

The feelings the therapist is experiencing are available to him (sic), to his awareness, and he is able to live these feelings, be them and communicate them if appropriate (Rogers 1961 cited in McLeod 187).

Such a relationship is also frequently referred to as being present with the person. The principles and beliefs that were the basis of Roger's counselling approach are major themes within PCC regardless of discipline.

van Weel-Baumgarten and Brouwers (2011) see the key to person centeredness in medical care as:

*…providing room for the patient's story through involvement in and beyond consultations; stressing the importance that a patient is seen as a person; attention for context as well as the symptoms or problems of that person, taking into account social, psychological and biomedical factors; an emphasis on a dialogue between patient and health care provider; exploring emotional cues and showing empathy; adjusting information and advice to the person's context, and framing it in a positive way and involving patients in decisions on the management of their illness. However, the patient-physician relationship is not one-sided. Therefore, paying attention to the person of the doctor with an awareness of the influence of the doctor's personal qualities on the practice of medicine is also a component of patient-centeredness (*35*).*

They reflect Roger's work in terms of also being aware of the doctor's personal attributes.

Cooper (2007) also highlights the relationship between client and practitioner in counselling as integral to PCC. Central to all definitions is the individual and generally the family carers. Epp (2003), concentrating on dementia care, notes Mitchell's comments that PCC is '…value-driven, focuses on independence, well-being and empowerment of individuals and families (14).

In a primary health care policy discussion on the difference between patient-centered and patient-focused care, Starfield (2011) contends that patient-focused care remains disease driven whereas PCC is holistic.

The Registered Nurses Association of Ontario in their 2006 Best Practice Guideline Supplement refer to client centred care and suggest:

 *…nurses embrace the following values and beliefs: respect, human dignity, clients are experts for their own lives, clients as leaders; client goals coordinate care of the health care team, continuity and consistency of care and caregiver; timeliness, responsiveness and universal access to care. These values and beliefs must be incorporated into, and demonstrated throughout, every aspect of client care and services (*3)*.*

Significant to note in this definition is the recognition of the responsibility of services. Further, the Guideline recommends that *…health care services must be organised and administered in ways that ensure that all caregivers, regardless of personal attributes, enact this practice successfully.*' (4).

Clearly services according to this Guideline have a responsibility to educate staff and have supportive structures and processes in place to enable PCC, however the Guideline remains focused on the client as the person.

Bowers (2012) similarly places the nursing home resident as the person in PCC and writes that PCC in nursing homes:

• *Seeks to eliminate the assembly line approach to care and embraces a philosophy of residents as individuals;*

• *Seeks to improve quality of care and quality of life for residents and leads to a more satisfied life;*

• *Means residents are given choices and are able to make decisions;*

• *Requires staff to alter work routines to accommodate resident preferences; and*

• *Requires staff to have relevant knowledge and decision-making authority (*13).

Kitwood (1997:8) was the indisputable champion of PCC in care of people living with dementia. He advocated for seeing the person rather than the dementia and valuing personhood which he described as '…a standing or status that is **bestowed** (emphasis added) upon one human being, by others, in the context of relationship and social being…'. While his work has undeniably had a major influence on PCC to suggest that personhood is 'bestowed' conflicts with the agency and independence of the person upon whom it is bestowed and implies a relationship of inequality. This contradicts a fundamental principle of PCC.

The consumer as central to PCC is challenged by the recognition of relationships

Notwithstanding this criticism, Nolan et al (2003) acknowledge it was through:

…the pioneering work of Tom Kitwood and colleagues at the Bradford Dementia Centre (Kitwood, 1988, 1989, 1990,1993, 1997; Kitwood & Bredin, 1992a,b; Kitwood &Benson,1995)

that person-centred care has been fully articulated, and there can be little doubt that Kitwood's ideas have provided a new sense of direction and purpose for practitioners (46).

The VIPS framework of Brooker (2006) builds on Kitwood's original work and she describes the main elements of her approach as:

Valuing people with dementia and those who care for them (V); treating people as Individuals (I); looking at the world from the Perspective of the person with dementia (P); and a positive Social environment in which the person living with dementia can experience relative well being (5).

In a review of the literature on person-centred care of people with dementia, Alzheimer's Australia Victoria (2008) synthesised the defining characteristics of person-centred care as being:

- *acknowledging the individual as an experiencing person in spite of the disease;*

- *offering and respecting the person's choices;*

- *using the person's history and biography in care;*

- *focusing on abilities rather than disabilities;*

- *supporting individual rights, values, and beliefs;*

- *providing unconditional positive regard;*

- *interpreting all behaviour as meaningful; and*

- *maximising potential and providing shared decision making (13)*

As noted, the primary focus of PCC has been on the client/person/patient (McCance et al 2011; Nolan et al 2004; Elliott & Freire Crameri 2006; Miller & Duncan ACSQ in HC 2011; Pelzang 2010; Stewart, 2001; NARI 2006) however, the conclusion proffered by NARI from reviewing the literature (2006) was that a partnership model better reflected and respected the expertise of both consumer and provider. This model may be a step toward PCC but remains at odds with most of the literature and policy directions which recognise the importance of privileging client' choice.

Another approach is to recognise the significance of interdependence by focusing on relationships explicitly. McCormack (2004) for example, concludes that person-centred nursing (or care) has four aspects:

• *being in relation (social relationships)*

• *being in a social world (biography and relationships)*

• *being in place (environmental conditions)*

• *being with self (individual values). (6)*

Further, Nolan et al (2003) support MacDonald who said that;

''…we need to subscribe to a relational view of the concept which sees human beings as belonging to a network of social relationships within which they are 'deeply interconnected and interdependent''. They continue: *Advancing similar arguments Clark (2002) contends that we can only fully understand an individual case by 'situating' it within a rich matrix of relationships and socio-cultural beliefs, …(47)*

It is clear in the latter part of this quote how the work of Heidegger, cited earlier in this paper, on the person always being situated has continued to inform current ideas. Perhaps a more person-centred argument would be to say *we* can only fully understand an **individual (not case)** by 'situating' them within a rich matrix of relationships and socio-cultural beliefs…

Nolan et al (2003) argue against the terminology and individualistic thrust of PCC. They champion a new model that is relationship-centric and recognise the need to include staff and families as 'persons'. They operationalised their ideas through the development of what they call 'The Senses framework', which:

captures the subjective and perceptual dimensions of caring relationships and reflects both the interpersonal processes involved and the intra- personal experiences of giving and receiving care. The 'Framework' is underpinned by the belief that all parties involved in

caring (the older person, family carers, and paid or voluntary carers) should experience

relationships that promote a sense of:

- *security – to feel safe within relationships;*

- *belonging – to feel 'part' of things;*

- *continuity – to experience links and consistency;*

- *purpose – to have a personally valuable goal or goals;*

- *achievement – to make progress towards a desired goal or goals;*

- *significance – to feel that 'you' matter (49).*

> *The definitions of PCC are challenged and the importance of continuity, belonging and having purpose alongside feeling you matter are introduced.*

This explicit inclusion of other stakeholders in the caring relationship amounts to a paradigm shift, supported by Nay et al (2009; 2013) but the argument for relationship-centred care, rather than PCC, is justified only if the person's relationships are not deemed to be integral to the situated person. That is, if the person is conceptualised as separate from their context which includes relationships. The insights of Heidegger (1962) on the situated *Being* ín and of the world demonstrate otherwise. Just as it is (increasingly at least) recognised that the mind/body split challenges capacity to fully understand the person, so too does a mind/body/context split. Each continuously interacts and impacts the other.

DIAGRAM 1 THE SITUATED PERSON
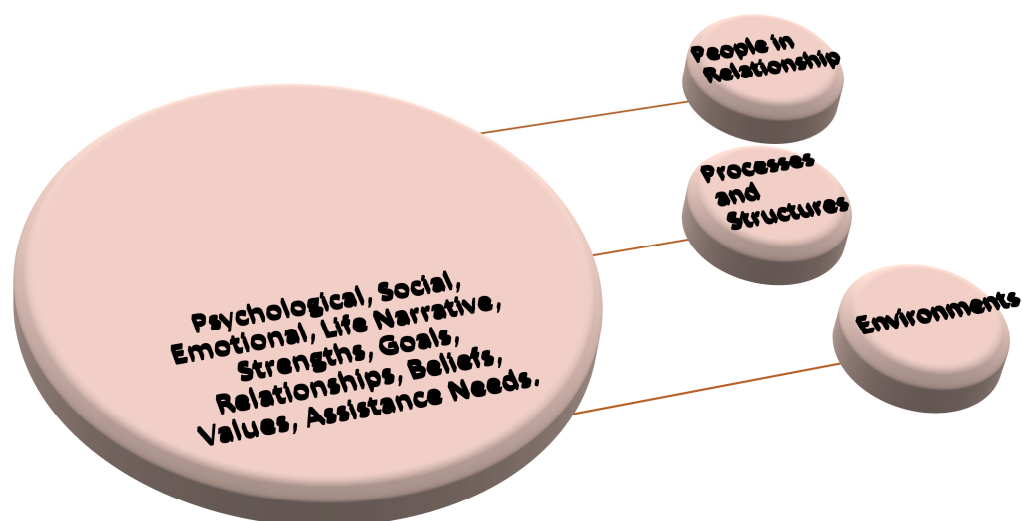
The listed constituents of 'the person' are examples and not intended to be comprehensive

So if the person at the centre of PCC is understood as inclusive of their situated context, then changing the terminology to relationship-centred only serves to unjustifiably confuse those who have already invested heavily in moving from the medical model to PCC.

Most of the descriptions and discussions of PCC do not include explicitly the organisational leadership, management, structures and processes, although Jacques and Innes (1998) recognised long ago that *for person-centred care to occur, staff need person-centred management* (Innes et al 7); Nay et al (2013) also argue for a 'whole of organisation' approach:

- *Leadership that models person-centred care in all actions and decisions – PCC is not just pulled out of the drawer for accreditation or something staff at the bedside have to enact;*

- *A PCC philosophy that is understood by all staff – not just a framed piece of paper to sit on the wall;*

- *Relationships across the organisaton that demonstrate valuing of employees as 'persons' – if staff are to be person-centred they need to see the philosophy modelled by management;*

- *Environments that value and support clients, families and staff and acknowledge the importance of supportive relationships to healing and well-being; and*

- *Flexible systems and processes that enable – or indeed force - staff to move away from a task/ disease orientation; for example documentation focussed on the 'doctor's orders' and 'nursing plan' and written about the client will invite medico-centric care whereas PCC documentation would be reflecting the client's goals and involvement in decision making (143)*

Leadership and role models that enable staff to BE person-centred and provide choice to consumers are vital.

SUMMARY

Although across the international literature there are multiple definitions of PCC and arguments to change the terminology and emphasis, it can be seen that there are common subthemes all of which aim for organizational and individual **wellbeing**:

- Having a whole of organisation philosophy and approach to care and support
- Respecting and valuing each individual as unique
- Recognising the need of all people to have purpose and to feel they matter
- Providing unconditional positive regard
- Actively listening to the whole person in context
- Focusing on strengths and goals and working with in a positive framework
- Recognising the significance of a positive social environment
- Supporting rights, values and beliefs
- Recognising that all behaviour is meaningful

- Supporting positive relationships across all stakeholders
- Enabling choice wherever relevant to the person and within an environment of respect for others.

So integral to PCC is choice, including consumers having the right to determine what services **they** need; when, where and how services are delivered and who delivers those services – in effect Consumer Directed Care.

CONSUMER DIRECTED CARE (CDC)

It is Innes et al (2006) who emphasise the notion that for PCC to be really embedded in care and support services, clients/consumers must be enabled to CHOOSE the services they want; rather than have service providers determine what consumers need. Innes et al contended that PCC is care that:

*...is focused on clients/users; promotes independence and autonomy rather than control; involves **services** that are reliable and flexible and **chosen by users** (added emphasis); and tends to be offered by those working in a collaborative/team philosophy (23).*

This quote also highlights the move in terminology away from patient/ client to consumer/end-user. The debate around this shift cannot be canvassed here other than to note that there is debate especially in relation to whether the term 'consumer' accurately reflects the relationships that exist within health care where choice is constrained by such issues as service availability, access, demand, consumer literacy and 'taking one's business elsewhere' is frequently not an option.

As with PCC the literature on CDC shows varying terminology used for giving choice and control to the consumer, however common principles apply:

The National Institute on Consumer-Directed Long-Term Services, says consumer direction is "a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive." Consumers assess their own needs, determine how and by whom these needs should be met, and monitor their services (Heumann 2003 1).

and

The importance of flexibility, choice in services, control and individualised care to disabled people and older people has been robustly stated (Morris, 1994; Douglas et al., 1998;

Priestley, 1998;Hardy et al., 1999; Kestenbaum, 1999; JRF, 1999; Simons and Watson, 1999; Vernon and Qureshi, 2000; Clark and Spafford,2001; Patmore, 2001; Raynes et al., 2001; Carmichael and Brown,2002; Holborn and Vietze, 1999; Simon et al., 2002; Stainton,2002; SWRDU, 2002; Vernon, 2002; Hawthorne et al., 2003;Francis and Netten, 2004), and is a key feature in perceptions of high-quality services (Innes et al 2006:16)

> *"a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive."*

The disability rights movement is credited with lobbying for and introducing CDC as a way of increasing 'choice and control in service provision' (Low et al 2012). The first model in Australia was introduced in WA in 1998 (KPMG 2012). Some form of CDC has been introduced in numerous countries including the US, UK, Austria, Denmark, France, the Netherlands, Israel, Canada, Germany and Sweden (KPMG2012; Low et al 2012). The principles are very similar – that is to increase consumer choice in services and responsibility for determining their own needs' and priorities. Rees (2010) adapting the National Institute on Consumer-Directed-Long-Term-Services definition Heumann (2003:1) describes CDC as 'both a philosophy and an orientation to service delivery that acknowledges that consumers have a right to choose. The main goal of CDC is to offer consumers greater control over their lives by providing them with the opportunity to make choices about their care, to the extent they wish to do so' (Wilson 2012, 2012a).

Reporting on a session held at the IAAG World Congress in 2001 devoted to arriving at a shared understanding of CDC, Howe (2003) writes that CDC has three distinguishing features:

- provision of cash benefits to enable clients to purchase services;
- there is not only one model of CDC, and
- that programs may provide cash benefits but not be called CDC.

In a Position Paper for the Brotherhood of St Lawrence Largy and Naughtin (2009) state that:

The term consumer-directed care is used to describe a mechanism where consumers have direct control over their allocated funds and these can be used flexibly to meet their needs. Services and equipment can be purchased from traditional service agencies, and funds can be used for options outside the formal service system. Consumer-directed care provides greater control and choice to the consumer and reduces reliance on case management services. It is increasingly used in aged care internationally and in the Australian disability sector to promote independence and achieve cost efficiencies v.

Models of CDC vary but essentially the differences relate to whether the consumer or another agent is provided directly with the funding (cash or vouchers) for care and who is charged with the consequent responsibilities such as hiring and firing, financial accounting and monitoring service quality.

Other variations in approaches to CDC are related to:

- *Functional and financial eligibility criteria,*
- *The number of eligible beneficiaries and the proportions opting for cash benefits,*
- *The range of services covered, with most limited to personal assistance,*
- *Benefit amounts and levels of payments,*
- *Options for combining varying levels of cash and services vs. an all-or-nothing choices;*
- *The balance of funding from general taxation and long term insurance premiums;*
- *Whether relatives can be hired and paid; and*
- *Provisions for quality assurance* (Howe 2003 7)

In addition, learnings from CDC evaluations have resulted in models offering more counselling and support of consumers and providers:

Cash and Counseling is an alternative approach to the traditional agency-based model for the delivery of Medicaid home- and community-based personal assistance services (PAS). The Cash and Counseling model provides recipients of PAS a flexible monthly allowance and places the consumer in control for managing their care (Sciegaj et al 2008: 82).

The Australian model, unlike others, is specific to care of older people and the description of CDC provided by the Australian Government is that:

*Consumer (or self) directed care allows people to have greater control over their own lives by allowing them, to the extent that they are capable and wish so to do, to make choices about the types of care services they access and the delivery of those services, including who will deliver the services and when (*DoHA 2013: 1).

Further that CDC in aged care is based on the following *key principles:*

- *Integrated – CDC should be integrated into existing programs as an optional mode of care delivery and operate within the constraints of the current legislative arrangements.*

- *Responsive – CDC should be responsive to the changing needs and circumstances of care recipients and carers, and enable adjustment of budgets and services to meet those needs.*

- *Inclusive – CDC should take into account the needs of care recipients and their carers and consider its contribution to, or impact on, the social inclusion of care recipients and carers.*

- *Equitable – Care recipients with the same or similar needs and circumstances should receive comparable allocations of budgets and services.*

- *Optional – CDC should be offered to care recipients as a voluntary option.*

- *Care recipient and carer-centred – CDC should take into account the needs and views of care recipients and carers and support them having control and choice over their care.*

- *Supportive – Care recipients and carers and providers should be provided with a range of support to make informed decisions and practise CDC, including education and advocacy.*

- *Sustainable – CDC should provide an affordable, long term option for delivery of care for Government that meets the needs of care recipients and their carers 2012: 2.*

The Australian Government definition places opportunity for choice at the centre

Although the models may differ in the extent to which consumers have control over funds and the names given to the models the intent is clear and that is to increase consumer choice and move away from agency or provider driven models of service provision.

SUMMARY

CDC has the same philosophical basis as PCC but has developed more as a funding model that provides opportunity for choice. CDC was introduced in developmental disability long before expanding to aged care. The focus of CDC is to give consumers the opportunity to make their own decisions about the services they receive. What service is provided, by whom, when and where has traditionally been up to the service provider and funding support has been directed to the provider. Under the principles of CDC funding support goes directly or notionally to the consumer. While the supportive rhetoric for CDC is strong, in reality choice is only as great as the accessible services and the capacity to 'buy' those services. Some CDC models have tried to address these barriers by including education and advocacy for consumers.

SYNTHESIS

The philosophy upon which both PCC and CDC are based is one that respects and values each situated person, the people with whom they relate, their values and beliefs and the right of all persons to experience well-being. For this philosophy to be realised in care and support services it needs to be reflected and supported in and through policies, budgets, structures, systems, processes and practice.

Taking account of the varying definitions, descriptions and elements of PCC and CDC reviewed for this Discussion Paper it is concluded that:

PCC is an all-encompassing, whole of organization approach to care and support services that maximises self-determination, choice, goal achievement, and well-being. Further the *person* is conceptualised as inescapably situated and thus capable of being known only through their continuous, ever-evolving experiences and relationships and their attributed meanings, values and beliefs.

CDC is generally well described by the Australian Government:

Consumer (or self) directed care allows people to have greater control over their own lives by allowing them, to the extent that they are capable and wish so to do, to make choices about

the types of care services they access and the delivery of those services, including who will deliver the services and when (2012: 1).

The term állowing' unintentionally suggests inequity in the relationship with the government/provider having the power to allow. More appropriate terms would be 'enables' or 'supports'. Enabling would also include ensuring consumer literacy and provider education. The definition could be enhanced with concepts from the NICDLTS and Rees definition:

"a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive." Consumers assess their own needs, determine how and by whom these needs should be met, and monitor their services (Heumann 2003 1). Although I would reject the idea that CDC is a philosophy; certainly it is based on a philosophy but it is an action-oriented service change and as Mansour (personal communication 2012) argues:

…the concept of CDC in the Australian context is much more about 'opportunity' to exercise greater decision making rather than an outcome per se. One entirely valid option for consumers is to continue to rely on professional guidance in determining the outcomes from their package (2014 personal communication)

CDC would then be understood as:

the delivery of services whereby informed consumers are given the opportunity and supported to assess their own needs, determine how, when and by whom these needs should be met, and evaluate their services according to their own expectations. Consumers thus have greater control over their own lives and well-being.

In the ideal world, CDC would be delivered according to a PCC approach and it could be argued that they are mutually constitutive. To date evaluations indicate that this is not always the case.

It is possible for direct payments to be made to consumers, for consumers to determine the services they need and who will provide them; but the provider staff either do not understand or reject PCC. In this case the 'HOW' of CDC may not reflect the philosophical

underpinnings. Similarly, individual staff members may be very person-centred in the HOW of their care, but the organisation rejects CDC.

Mansour argues:

that Person Centred Care is a form of professional practice based around principles of consumer involvement in decision making. It has a continuum from informed consent through to much more significant levels of input into decision making. It is embedded in many professions. Thus, the professional practice of person centred care would still continue as a valid and legitimate form of professional practice irrespective of any roll out of CDC packages.

The problem with separating professional practice from a whole of organisational approach, is that staff members may be confronted with organisational systems that negatively impact their ability to provide person-centred care. For example, task and procedurally focused computerised care planning systems; or other structures and processes that inhibit staff to deliver person-centred care and result in fragmented approaches to PCC across the organisation.

Summing up, PCC and CDC have arisen from the same philosophical ground but they are not the same thing. Understanding the differences and using the terms consistently across policy, governance and practice will enhance communication and ultimately, care outcomes.

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