Person Centred Planning:
A review of the literature

Strengthening person centred planning in the Community Participation program

NSW Department of Ageing, Disability and Home Care

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Overview

This is a review of literature about person centred planning practices (PCP) and approaches. Literature has been reviewed with the intention of illuminating:

- the features of PCP and practices
- outcomes of PCP
- issues that need to be considered in the development of person centred practices.

The literature review demonstrates that person centred approaches can achieve significant outcomes for individuals with disabilities. It also demonstrates that it is an approach that requires fundamental changes in the way that service systems relate to people with disabilities.

The literature review discusses the very significant differences between PCP and other traditional individual planning processes (IPP) and notes the problems that arise when PCP is not deeply understood which results in IPP approaches being reinterpreted with the rhetoric of PCP without the necessary changes in underlying thinking and practice.

The literature highlights that there are significant barriers to the successful development of person centred approaches that need to be addressed. If person centredness is to be achieved, attention needs to be paid to:

- Developing a deep understanding of the complexities of person centrednessness
- Fundamentally changing organisational structures and processes
- Ensuring strong leadership to support the development of person centred approaches
- Ensuring that people with disabilities, families and staff are well supported and educated
- Ensuring that systems and practices are in place to achieve the implementation of person centred initiatives
- Developing commitment, leadership, and support at a systemic level to facilitate person centred development by the service sector and community.

Introduction

This literature review has been conducted to inform the thinking that underpins a practice guide and workshops that will be developed and delivered by a consortium comprising Australian Catholic University (ACU), Sherwin & Associates and Ellis MacRae & Associates. The project has been commissioned by the NSW Department of Ageing Disability and Home Care (DADHC) for the Community Participation Program.

The approach taken in considering relevant literature for inclusion in this review has been to seek literature that focuses on PCP (person centred planning), person centred approaches and person centred practices through empirically validated observations, evaluations, reviews and opinions.

Literature searches of academic databases, Internet and libraries have been undertaken using 'PCP', 'person centred', 'disability' and related terminology and spelling used in other countries such as 'learning disability' and 'centered'. The literature search yielded a total of 78 articles and books that have been used to inform this literature review, with a total of 55 articles and book chapters being used directly.

It is clear from the literature reviewed that the term 'Person centred Planning' (PCP) is used to describe and relate to a broader set of crucial elements, which bring about significant change in the lives of people with disability. Thus, while the term 'PCP' is used frequently, it is effectively a shorthand term that encompasses:

- Person centred approaches and thinking about relating to, empowering and supporting people with disabilities
- Person centred structures that support and empower people with disabilities to lead a good life and
- Person centred environments (Kilbane & McLean: 2008).

This literature review could therefore be accurately viewed as relating to 'person centredness'.

Features

PCP had its origins in North America in the late 1970s and 1980s as practices to promote the adoption and implementation of the principle of normalization, and as a reaction to dissatisfaction with individual program planning tools (O'Brien & O'Brien, 2002; Robertson et al., 2005). Mount (2002), one of the originators of PCP, describes it as "both a philosophy and a set of related activities that leads to simultaneous multilevel change" (2002, p. xxi) and O'Brien & Lovett (as cited in Kim & Turnbull, 2004) describe it as essentially a family of approaches to organise and guide community change in alliance with people with disabilities, their families and their friends.

Sanderson summarizes PCP as:

> *a process of continual listening, and learning; focussed on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends. It is not simply a collection of new techniques for planning to replace Individual Programme Planning. It is based on a completely different way of seeing and working with people with disabilities, which is fundamentally about sharing power and community inclusion. (2000:2)*

Holburn (2002) states that it provides a way to understand the experiences of people with disabilities and, with the help of allies, to expand those experiences through reducing social isolation and segregation, facilitating the establishment of friendships, increasing opportunities to engage in preferred activities, developing competence and promoting respect (Holburn, 2002).

Mount (2002) explains PCP as a process of listening carefully to the hearts of people with disabilities and, with them, imagining a better world where they are valued, contribute and belong.

PCP requires a broad range of actions at individual, organisational and systemic levels to support and facilitate the development of person centred plans (O'Brien & Mount, 1987;

O'Brien & Towell, n.d.; Duffy, 2004; Mansell & Beadle Brown, 2004; Beadle Brown, 2005; Cambridge & Carnaby, 2005b)

When engaging in the activities of developing an actual plan therefore, the following are considered essential:

- Convening a group of individuals committed to the person for whom the plan will be developed, including, at the centre of the group, the focal person;

- Gathering information about who the person is, their passions, needs and desires;

- Developing a vision or dream for a desirable future based on the person's gifts, interests and desires

- Developing a plan to achieve the vision or dream

- Taking actions to achieve the vision or dream

- Reviewing actions and making changes to the plan as needed (Kilbane & Thompson 2004b; Kim & Turnbull, 2004; Medora & Ledger, 2005).

Central to any PCP process is ensuring that:

- The person is kept at the centre of the process

- The person, family and friends are partners in the planning

- The resulting plan reflects what is important to the person, their capacities and the supports that the person requires

- The plan reflects what is possible, not just what is available now

- The plan uses, whenever possible, natural and community supports

- The plan results in actions that about the person's life, not just services

- Activities resulting from the plan foster opportunities and skills to achieve personal relationships, community inclusion, dignity and respect

- The plan results in action, review, ongoing listening and further action (Kilbane & Thompson 2004b; Kim & Turnbull, 2004; Medora & Ledger, 2005).

Whilst the above represents activities and principles that guide the development of a plan, it needs to be understood that the adoption of PCP impacts dramatically on professionals and the structures that support people with disabilities. Mount (2002) states that PCP requires those in human services to radically re-examine assumptions, commitments and

investments, and to change the way that they relate to people with disabilities, each other, and their organisations. This view of PCP extending beyond an individual plan, to a broad collection of practices that requires widespread and fundamental system and organisational change, is common in much of the literature about PCP (O'Brien & Towell, n.d; Parley,2001; Kendrick, 2004; Michaels & Ferrara, 2005; Robertson et al., 2007a; Robertson et al., 2007b; Routledge, Sanderson, Greig, n.d; Kilbane, Thompson & Sanderson, 2008). It involves "multifaceted, long-term interventions that entail a good deal of problem solving and organisational accommodation" (Holburn, 2002:251).

Since the early development of PCP in the late 1970s and 1980s, person centred approaches have become an increasingly dominant approach to supporting people with disabilities. In England, PCP plays a central role in the disability service system and has been systematically adopted through its underpinning of government policy such as the Department of Health White Paper 'Valuing People' (Felce, 2004; Kilbane & Thompson, 2004b; Kilbane, 2008) and the subsequent adoption of PCP as a policy goal (Dowling et al., 2007). Indeed, PCP has moved from the edges of service systems to now be integral to many service systems (Smull & Lakin, 2002).

Differences between person centred and other planning processes

PCP was not the first approach to planning for individuals with a disability. Earlier versions of individual planning (IPP) also worked on the development of plans for individuals based on what the person wanted (Mansell & Beadle-Brown, 2003; Centre for Development Disability Studies, 2004; Kilbane & Thompson, 2004b; Michaels & Ferrara, 2005). These plans, however, tended to focus on what a particular service had to offer based largely on professional assessments (Callicot, 2003). PCP does incorporate some of the aspects of individual planning and assessment processes but also has fundamental differences (Mansell & Beadle-Brown, 2003; Sanderson et al., as cited in Kilbane & Thompson, 2004b).

Some authors view the development of PCP as a step in the evolution of IPP (Dowling, Manthorpe & Cowley, 2007), while others point to the distinctive differences that make it a

revolutionary idea, even a paradigmatic shift (Garner & Dietz, n.d.). Garner and Dietz view it as a paradigmatic shift because IPP offered only what the system had to offer even if it did not fit with an individual's personal situation and aspirations. PCP however offers support to achieve the individual's aspirations irrespective of what the system currently offers. Kilbane and McLean (2008) note that PCP has elements of both evolution and revolution in that IPP processes brought attention to the individualisation of planning. The individualisation however only extended to making professionally judged change. Sanderson et al. (1997) note significant differences in the underpinning beliefs, values, practices and consequences of the planning between PCP and IPP.

Some of the distinctive differences between PCP and traditional IPP are:

- PCP focuses not only on the individual aspect of planning as with traditional IPP, but adds consideration of the individual's wishes and preferences (Callicott, 2003)

- The person centred plan looks beyond what is available at present to what might be possible, whereas the traditional individual plan offers from what is currently available from a service (Callicott, 2003)

- Person centred approaches rely less on the service system by organizing individualized, natural and creative supports to achieve meaningful goals based on an individual's strengths and preferences (Garner and Dietz, n.d.)

- PCP attempts to situate power and control with the focus person and their allies, whereas, in IPP, the power lies with professionals (Mansell & Beadle-Brown, 2003 Kilbane & Thompson, 2004b; Michaels & Ferrara, 2005)

- PCP looks towards natural supports rather than relying on paid support as occurs with IPPs. Services are required to be responsive to the changing needs of the individual by tailoring services in a way that makes sense to the person (Mansell & Beadle-Brown, 2003; Kilbane & Thompson, 2004b; Michaels & Ferrara, 2005)

- Traditional planning models focus on the person's deficits and needs whereas PCP focuses on the person's gifts, capacities, dreams and desires (Mansell & Beadle-Brown, 2003; Kilbane & Thompson, 2004b; Michaels & Ferrara, 2005).

These differences can present challenges for staff and organisations because traditional planning models "required that staff behaved in a synchronised and standardised way. Person centred planning, requires that staff have a flexible and responsive approach ... guided by the principles of good planning rather than standard procedure" (Sanderson, 2000:2).

Person centred approaches and thinking

PCP requires those who are involved to re-examine assumptions, commitments and investments, and to change the way in which they relate to people with disabilities, each other, and their organisations (Mount, 2002). As such, it requires particular approaches and thinking.

Traditionally, service provision has been characterized by diagnosis, prescription, assessment of needs and actions to address the needs (Callicott, 2003). PCP requires a change of thinking about people with disabilities and service provision so that the person and what is important to them is at the centre of all thinking. Kilbane et al. (2008) discuss the difficulty that such a shift in thinking may make because the differences sometimes appear subtle. They note that it is easy to see the similarities between individual planning and PCP and to believe that what is being achieved is person centred.

> *The more that we think of person centred thinking, planning and practice as more of the same as we have always done, then it is more likely that PCP morphs in to exactly that, as we minimise the differences and only look for similarities. The power of person centred practice lies in these differences"* (Kilbane et al., p.30).

An example of the subtlety in the shift of thinking can be seen in separating notions of what is important for a person, to what is important to a person. It is important to pay attention to both what is important for and what is important to, but it is too easy to focus only on one and not the other. Thus tensions may arise from the clash of such ideas. It needs to be recognised that both ideas are important (Duffy, 2004; Kilbane et al., 2008).

There is also a danger that choice is interpreted as a range of predetermined options; person centredness becomes enacted as merely asking people for their views, rather than acting on them; participation becomes a euphemism for asking people to attend a meeting and empowerment becomes just consultation (Cambridge & Carnaby, 2005b).

Person centred approaches require those who are involved to use resources flexibility to achieve what is important to the person. The fundamental difference to traditional approaches to service provision is that the service works to, adjusts to, and provides to the

person what they want in life, rather than the person being expected to fit into an existing service. Person centred approaches works with the generic mainstream services and the community rather than limiting actions to what can be provided by the specialist disability sector (Kilbane et al., 2008).

Listening is central to person centredness. It is a process that calls for everyone involved to focus on and listen to what is important to the individual now and in the future; to pay careful attention to the person's capacities and choices; and to work to overcome barriers, to make what is important to the person a reality through the alliance of the person's own network, family and the community. Full attention needs to be paid to the person and their life, drawing out how things are now for the person, and how they should be.

> *Listening in person centred planning involves earnest attention and intention. Attention to body language, words, meaning, inspirations and aspirations. Intention to understand, to know, to connect with, to make possible, to be alongside and to support a person (Kilbane et al., 2008, p.31)*

Kilbane et al. note that the deep listening that is required often creates a tension between how things are right now and how they should be. This can challenge the ethics of practitioners because it invites engagement in another person's life. It will illuminate contradictions between a service's espoused values and actual performance (O'Brien, 2002).

Traditionally the power to determine what a person needs and how to meet those needs has been held by professionals (O'Brien, 2002). Power is a central issue to PCP because people with disabilities are often powerless. PCP attempts to address the balance of power as much as possible by requiring a shift in this power structure to share power with the person and their supporters (Sanderson, 1997; Sanderson, 2000). PCP does not take away the role of the professional, rather it uses the expertise and knowledge of professionals to achieve what is important in the lives of people with disabilities (Sanderson, 2000).

Routledge, Sanderson & Greig (n.d.) note that sharing power and listening carefully to people with disabilities and their families is particularly difficult because of the lack of a history of effective partnerships, which causes families and self advocates to be defensive

and sceptical, and because of the prominence that has been given to professionals being in the planning role.

Sanderson (2000) suggests that keeping the person firmly at the centre of the planning process means ensuring the person is consulted throughout the planning process; ensuring the person chooses who to involve in the process; and ensuring the person chooses the setting and timing of meetings.

Keeping the person at the centre of the planning process means ensuring that the person is thought of in the context of their family, friends and community. As such, the process seeks to share power not only with the person at the centre of the planning but also their family and others that they have invited to participate in the planning processes (Sanderson, 2005). The shift of power from professionals to family is important because family care about the person in a different way to anyone else and will likely be involved in the person's support for their entire lives (Sanderson, 2005). Gregson (2007) states that families have the emotional commitment drive and motivation to be one of the main driving forces in PCP. She states that family members often make the best PCP champions. They will be with the person for the long haul and have a vested interest in ensuring that plans evolve and that action is taken.

Whilst the power sharing with the person and their family is a key principle of PCP it has also been shown to be key in developing good outcomes. LeRoy et al. (2007) found that the presence of family, friends or advocates at planning meetings is an important ingredient in developing creative problem solving and strategies in the planning process.

Those who seek to develop person centred approaches will need to develop strategies to support people with disabilities and their families through the planning processes because many have not traditionally been adequately involved in individual planning processes. The Centre for Developmental Disability Studies (2004) cites concerns about the involvement of individuals and families in individual planning which includes the development of many plans when clients were not even present at their own meetings; a high percentage of plans

being developed without family involvement; and individuals and families not being able to contribute meaningfully to the development of plans because of their perceived low status relative to that of professionals.

Kendrick (2004) cautions that many people and their families are unaware of what is possible in their lives and that achieving innovative options may entail more difficulties than accepting what is currently available and will need to be well supported through the planning processes.

Dunst et al (2002) developed concepts of family centred practice, to help practitioners become more conscious of, and move away from, professionally centred practice. Kim & Turnbull (2004) argue that during the transition to adulthood, planning is required that merges PCP and family centred planning into a new approach they call 'person-family interdependent planning'. They see this as an important way to plan for young adults with severe disabilities and their families to 'buffer' them during a particularly chaotic and stressful period.

Family centred planning approaches have primarily been developed around children's support and focus on supporting the whole family not just an individual (Kim & Turnbull, 2004). Family centred planning sees "the family as the unit of attention, and organises assistance in a collaborative fashion and in accordance with each individual family's wishes, strengths, and needs" (Allen & Petr, as cited in Kim & Turnbull, 2004). Therefore a person-family interdependent planning approach looks at the person and their vision for the future but also looks at the needs and assistance that is needed for the whole family.

From the implementation of the Valuing People initiatives in England, Routledge & Gisham (2004) noted that training focused on staff, to the exclusion of families and self advocates. This highlights issues in the extent to which the family and the person can be involved if there is no investment in the capacity of families.

The common tools

PCP does not involve or emphasise the use of any particular tool or methodology; rather, it refers to a range of practices that share common principles and characteristics which have been described in the previous section.

The focus must therefore be on understanding and enacting the principles and characteristics, rather than focusing only on particular tools.

Some of the better known tools that embody the principles of PCP include: Individual Service Design, Personal Futures Planning, Lifestyle Planning, McGill Action Planning System, Essential Lifestyle Planning, Outcome Based Planning, Planning Alternative Tomorrows with Hope,(Callicott, 2003; Robertson et al., 2005), Circles of Support (Barrett, 2007), Group Action Planning (Garner & Dietz, n.d.).

The difference in the various tools is mainly about whether the focus is on longer term planning or day-to-day life issues and how the information is gathered (Robertson et al., 2005). It is not possible within this literature review to discuss each tool in great detail. Some of the features and differences between the four most commonly used tools are summarized below:

McGill Action Planning System (MAPS)

MAPS was first developed for use in planning inclusion for children in schools but is now also used with adults. There is a focus on processes that gather information about the person; develop a 'dream' of the future whilst also acknowledging 'nightmares' or fears of what might happen in the future. Plans are made and implemented to move towards the 'dreams' while avoiding the 'nightmares' (Sanderson, 2000). It has been noted that it is a good information gathering tool that is often used in the early stage in the planning process. It focuses on identifying the person's gifts and needs and working out plans to build on these (Stalker & Campbell, 1998).

Planning Alternative Tomorrows with Hope (PATH)

PATH is another PCP tool that develops a vision of a desirable future that the plan works towards. However it differs from MAPS in that is designed for planning teams where the person can clearly describe their own dream or where others in the planning team know the person very well and can articulate the person's dream. It doesn't focus on gathering information about the person now but is a way of planning direct and immediate action. PATH starts with the dream and then works back to what it takes to reach the dream (Sanderson, 2000).

Personal Futures Planning (PFPs)

PFPs involve getting to know the person and what their life is like now, developing ideas about what he or she would like in the future and taking action to move towards this desirable future. The process involves exploring possibilities in the community and looks at what needs to change in services (Kilbane & Sanderson, 2004). It looks at the person's life in terms of five outcome areas in the person's life and looks at what is working well that can be built on. It also develops a vision of a desirable future and works on what it will take to achieve the desirable future (Sanderson, 2000).

Essential Lifestyles Planning

Essential Lifestyles Planning was developed for people with severe disabilities and was used with people moving out of institutions (Stalker & Campbell, 1998). It is a tool that looks closely at the person's life now and Sanderson (2000) notes that it is a good tool for highlighting what is not working well at the moment. It doesn't look at the person's dream, but focuses on support that is to be provided on a day-to-day basis in a way that makes sense for the person (Sanderson, 2000).

Outcomes

The body of research on PCP has been growing in recent years and clearly demonstrates that PCP can be effective (Robertson, 2007a). A common concern about PCP, however, has been the lack of large studies to measure its widespread effectiveness (Holburn, 2002; Mansell & Beadle-Brown, 2004; Beadle-Brown, 2005). Emerson & Stancliffe (2004) respond by stating that the available case studies and evidence across medium to large sized environments makes it reasonable to conclude that PCP can be effective.

The largest international study of the outcomes of PCP was undertaken by Robertson et al. (2005) with 93 people with intellectual disabilities. Their study, which was conducted over a two year period in four different localities in England, demonstrated that PCP produced significant outcomes in many areas of peoples' lives. The study found that whilst no change had occurred in people's lives prior to the introduction of PCP, clear positive changes were apparent after the introduction of PCP in the areas of:

- Social networks
- Contact with family
- Contact with friends
- Community based activities
- Scheduled day activities and
- Choice making.

While these outcomes were highly significant, the research also demonstrated that of the 93 participants in the study, only 65 actually had plans developed during the study period indicating difficulties, even in service systems that adopt PCP, in ensuring that the plans are actually developed for all intended recipients. They found that the probability of plans being developed was likely to be linked to issues of leadership, staff stability and the existence of prior person centred approaches. However the strongest predictor of plan development was attributed to the commitment of the facilitator to PCP.

Their research also showed that people with mental health, emotional or behavioural problems were less likely to receive a plan, and if a plan was developed for them, they were less likely to benefit in the areas of social networks, contact with friends and family, choice, hours of scheduled activity and number of community activities.

People with autism, people with restricted mobility and people with health problems were also less likely to receive a plan, but if they did have a plan developed, people with health problems were more likely to benefit in the area of contact with friends and people with restricted mobility were more likely to benefit in the areas of contact with family, hours of scheduled activity and community activities.

Overall men benefited more in the areas of hours of scheduled activity and contact with friends and women benefited more in the areas of community activities and choice.

Outcomes, with the exception of contact with friends, were not linked to participant ability but were linked to participant characteristics of mental health, emotional or behavioural problems, autism or health problems.

Interestingly this study also demonstrated that, although there were initial direct training and implementation costs associated with the introduction of PCP, "overall, PCP was found to be largely cost neutral" (Sanderson, Thompson & Kilbane, 2006: 20).

The literature on the outcomes of PCP show that considerable work needs to be undertaken to ensure that good outcomes can be achieved for all individuals. Everson & Zhang et al. (as cited in Robertson et al, 2007a) found that plans for people with behaviour, communication or social skill difficulties were less likely to achieve goals, however, Medora & Ledger (2005) found that PCP processes produced good outcomes for people with complex needs, dual diagnoses and people with communication difficulties, but that there was a need to provide supplementary training in communication skills to support the planning processes and increase the involvement of people with communication difficulties.

The difficulties in achieving planning goals for people with behaviour, communication or social skill difficulties may be linked to deficiencies in service systems in providing appropriate supports to individuals with behavioural support and complex health needs, as described by Epstein Frisch, van Dam & Chenoweth (2006), rather than factors associated with the effectiveness of PCP.

Robertson et al (2007a) also found that people with mental health, emotional, behavioural problems, autism, health problems and restricted mobility were less likely to have plans developed.

Another significant study was conducted by Holburn et al. (as reported in Robertson et al., 2007a). In a longitudinal study involving 37 individuals living in institutional settings, they compared outcomes for 19 individuals whose planning involved person centred approaches with 18 individuals who used conventional individual service planning. The results of their study demonstrated that the use of PCP hastened the move to community settings and resulted in increased outcomes in the areas of autonomy, choice making, daily activities, relationships and satisfaction when compared with those individuals for whom conventional individual service planning tools were used.

In a project that involved PCP for 26 individuals with widely varying support needs, Medora & Ledger (2005) found that people with disabilities and their families enjoyed the experience of PCP and that it resulted in increased involvement of family and friends. They found that there was increased clarity about individuals' hopes, aspirations and interests and anecdotally found that people with disabilities were in more control of planning processes. They found that PCP was particularly helpful in the transition from school to adult services and transitions between living situations; that it led to more creative solutions and that many of the wishes and aspirations were relatively modest and easily achieved within existing resources.

Parley (2008) found significant improvements in the areas of respect, choice and taking part in everyday activities as the result of the implementation of a person centred model of support that was used by a disability support organisation. They found, however, that there were few gains in power sharing, major life decisions and family involvement. They attribute the low outcomes in these areas to the fact that the project focused mainly on person centred practices in care, whereas if PCP, in addition to person centred practices, was used it would have been multi-disciplinary and led to different outcomes. They conclude that for PCP to be most successful it needs to be linked to practice throughout all levels in the organisation.

Johnson (2007) cites the results of feedback from care managers in England that demonstrates that care managers involved in PCP found it to be a good way of getting to know people with significant disabilities better; provided a structure to work in a more preventative way; kept managers on task; and that the plans provided a strong, clear evidence to support requests for funding and resources.

Dumas et al. (as cited in Robertson et al., 2007a) found from interviewing 13 people who were involved in PCP that although needs and desires were identified, there were many instances where goals were not implemented. They reported that this was because of a lack of viable service or support solutions and that most participants believed that they were limited to existing service options and were not able to gain access to individualized options.

Towell & Sanderson (2004) note that an outcome of person centred philosophy and methods is that it is an effective way of engaging the hearts, minds and skills of potential allies in service reform. They note that a common reaction to serious engagement in PCP or training is to starkly see the gap between peoples' current lives and what could be possible which harnesses strong motivation for change. Along similar lines, O'Brien (2004) states that, when well implemented, PCP aligns the person and their allies around a common understanding of what is desirable for the person now and in the future; clearly articulates choices that are made about how the person wants to live and be supported as a valued community member; generates creative solutions to overcome constraints and barriers;

defines locally relevant strategies to negotiate for required mainstream and specialist resources; results in occasions for participants to get together to update and revise their shared understandings.

Mansell & Beadle-Brown (2004) state that in the absence of large scale studies on PCP, it is reasonable to assume that some of the problems associated with earlier individual planning processes may also present problems for PCP processes. They state that individual planning processes often resulted in paper exercises that did not translate into action and were not well-connected to the real issues for people with disabilities and these features also may be an issue in poorly executed PCP actions.

Mansell & Beadle-Brown (2004) cite evidence that staff often misjudge the receptive language skills of people with intellectual disabilities and this may impact on the effectiveness of PCP processes. They suggest that the extent to which people can understand choices and decisions may be limited and needs to be assessed. They state that communication difficulties, complex support needs and behaviour issues are not insurmountable problems in achieve person centred goals. They cite case studies that demonstrate that irrespective of the level of disability or complexity of support needs individuals can have close personal relationships. This concurs with O'Brien's (2004) view that failure in PCP may reflect an inability to adequately assist a person's participation or communication.

Holburn (2002) calls for systematic assessment of the extent to which person centred planners adhere to the process of PCP and the outcomes of PCP activities. Others such as Evans (2002) have argued that it is neither desirable, nor necessary, to apply systematic evaluation processes to PCP because of the non-scientific basis of PCP.

Whilst the research into the outcomes of PCP show that it can be highly effective, Cambridge & Carnaby (2005b) express concern that the good outcomes associated with PCP may be short term gains, that there appears to be no research into the long term

outcomes of PCP, and that therefore further research is required to verify the long term sustainability of PCP.

Considering the barriers/issues

Whilst studies on the outcomes of PCP demonstrate that it is an effective way of improving quality of life in many areas (Medora & Ledger, 2005; Robertson et al., 2005; Johnson, 2007; Robertson et al., 2007a; Parley, 2008), it has also been demonstrated "that there are considerable difficulties encountered in such planning systems and that if these difficulties go unaddressed, scepticism and resistance to PCP may ensue" (Robertson et al, 2007a). Similarly Routledge, Sanderson & Greig (n.d.) note that:

> *if decision-makers treat PCP approaches as simple changes they are almost guaranteed to fail because they will neglect a careful and well thought-through implementation effort (p.4).*

The literature appears to concur on the effectiveness of PCP when it is conducted well, but is also clear that there are many difficulties that may be encountered along the way which need to be dealt with (Mansell & Beadle-Brown, 2004) and that when PCP gets bogged down in obstacles and resistance, the danger is that planning efforts can dissipate into previous methods of service provision Holburn (2002).

> *If PCP is introduced without the understanding that it is based on a completely different way of seeing and working with people with disabilities then it will have little impact ... Furthermore services that ignore individual programme plans are liable to ignore person-centred plans in just the same way. So clearly there needs to be a shift in the values and attitudes of the service providers for PCP to be effective. (Sanderson et al, as cited in Parley, 2008)*

In England where PCP has been adopted nationwide, there have been concerns about maintaining the quality of PCP in the face of rapid implementation. Some problems cited during the implementation of the 'Valuing People' initiatives in England include:

- Failure by organisations to really change how people are listened to and responded to resulting in superficial changes
- Focus on staff training to the exclusion of families and self-advocates
- Failure to pay attention to the implementation of plans
- Disconnection between seeing what is important to people in the process of PCP and how resources are allocated and used

- Focus on technical training and failure to pay attention to follow up support, management action, and embedding person centred values in organisational cultures

- Implementation of PCP without good connections to other plans and strategies

- Failure to get person centred plans developed for the main target groups

- Failure of organisations to work effectively together. (Routledge & Gotham, 2004).

This list of issues highlights the many barriers that need to be considered. The following sections of the literature review highlights significant themes that emerge from the literature regarding the adoption of PCP.

Developing a deep understanding of person centredness

A significant issue that has been identified is the tendency to treat PCP as a simple process. Medora & Ledger (2005) note that there is a "paradox between the apparent simplicity of PCP and the complexity of doing it well" (p. 150) and O'Brien et al. (as cited in Holburn, 2002) see the failure to properly understand the PCP process as a significant reason for plans not working. The illusion of the simplicity of PCP has also been discussed at some length by Kilbane and Thompson (2004b) who state:

> It sounds so simple. Read logically, it makes sense to us. When we first explore what PCP means, it has a visceral 'rightness'. It feels as though the concept expresses all we have ever aspired to in our professional practice. ....we like to think that we are warm, caring individuals who would not dream of putting someone we work with anywhere else than in the centre of their life planning......only by constantly exploring and revisiting the PCP approach will we truly be able to practice in a person-centred way and understand the implications of our actions (pp28-29).

They go on to state that it is essential to gain a deep understanding of PCP and its implication or there is a risk that all that has been learned is the rhetoric of PCP. This view is supported by many researchers and practitioners of PCP who all discuss the need to understand the complexity and wider implications of PCP (O'Brien & Towell, n.d; Parley,2001; Mount,2002; Holburn, 2002; Kendrick, 2004; Michaels & Ferrara, 2005; Robertson et al., 2007a; Robertson et al., 2007b; Routledge, Sanderson, Greig, n.d; Kilbane, Thompson & Sanderson, 2008).

PCP has also been observed to fail when person centred value bases and a real understanding of person centred approaches are not ingrained in services. Because of the fundamental culture shift required, the messages consistent with PCP must be given frequently and consistently (Routledge & Gitsham, 2004; Gregson, 2007; Sanderson as cited in Holburn, 2002) and Medora & Ledger (2005) found that managers need to own the values of PCP and ensure that they lead by example if good outcomes are to be achieved.

Holburn notes that in the face of the complexity of PCP "it is not surprising that it is easier for organisations to adopt the language of person-centered planning as an alternative to practicing person-centered planning" (2002:251-252). Ramsey (2007) highlights some of the complexities that need to be considered when he notes that people with disabilities, and families, may choose from what they think might be on offer, from a fixed menu of options and based on limited experiences. They may not have been given ideas about what a positive future might look like. He notes that in the quest to be highly positive in PCP, barriers to supporting people to have desirable futures, the vulnerability to social devaluation, and any manipulating influences on people's choices are often not named.

Organisational structures and processes

Organisational structures appear to play a vital role in whether or not PCP is effective (Dowling et al., 2007). Routledge, Sanderson & Greig (n.d.) state that PCP is a philosophy and process that requires fundamental organisational change because it will come into conflict with existing practices and cannot be just added on to existing organisational practices. This will require many organisations to change existing practices in the areas of resource allocation, operational procedures, staff priorities and strategic planning. O'Brien & Towell (n.d.) caution against putting too much emphasis on making person centred plans without investing in culture change in organisations. Further, Michaels & Ferrara (2005) observe that PCP alone does not guarantee good outcomes for individuals. It is subject to misapplication because of systemic barriers which must be addressed if PCP is to be successful. In England the link between service and system management and PCP has been made clear in the 'Valuing People' initiatives (O'Brien & Towell , n.d.; Cambridge & Carnaby, 2005a).

Cambridge & Carnaby (2005b) argue that in order to operate from a person centred perspective, services need to devolve authority and resources to service users and staff and structures need to be non-hierarchical with lateral management systems. This view is supported by the work of Mansell & Beadle-Brown who note that "the bureaucratization of management processes and the reservation of funding decisions to higher-level managers removed from direct contact with service users" (2004:5) are impediments to effective PCP.

Medora & Ledger (2005) observe that difficulties in PCP can occur because existing organisational policies are contradictory to the philosophy of PCP. They found that PCP needs to be embedded in organisational processes and that "it requires a radical and complex review and redesign of service delivery if real shifts in power are to occur" (p. 168). Kilbane et al. (2008) discuss the difficulty in achieving responsive action within existing organisational structures and allocation of professional responsibilities that are common in service provision. They state that organisations need to work out ways of ensuring that the intention of applying person centred approaches can be achieved alongside organisational goals.

Structural and organisational practice issues have been cited as common reasons for person centred plans being developed and remaining in filing cabinets, never to be implemented (Centre for Developmental Disability Studies, 2004). Kilbane et al (2008) note the ease with which the organisational culture may emphasise achieving multiple targets, meetings, hierarchies and crisis management, leaving plans unimplemented. Kendrick (2004) discusses how much easier it is for organizations, when faced with multiple priorities, to offer people a selection from an existing service rather than create something from scratch that is built around a person's particular needs.

Routledge, Sanderson & Greig (n.d.) point out the importance of introducing innovations at all levels, across all areas of the organisation if PCP is to succeed, however they also advise that PCP should be introduced gradually.

O'Brien & Mount (1987) assert that PCP processes call for investment in five areas of organisational activity that can result in renewing organisations. They observe that if an organisation cannot invest in the following inter-related activities, PCP "is likely to become and empty ritual" (p.2):

- At the individual's level, **person centred plans** develop images of desirable futures and strategies for moving towards those futures for individuals
- The PCP needs to be supported by **interactive problem solving** activities involving small groups of people in the creative management of day-to-day issues involved in efforts to implement person centred plans and redesign organisational efforts
- Time and resources will need to be invested in **strategic redesign** to develop new community opportunities and developing connections to pave the way for the PCP of individuals to be successful
- The organisation will need to engage in **systematically evaluating** the effectiveness and efficiency of the organisational changes
- **Structured reflection** needs to be built in to provide opportunities consideration of ethical issues and deepening understanding of the issues.

Robertson et al. (2007a) emphasise the need to balance the desire to develop person centred plans for everyone with capacity to deliver them in terms of the required time, energy and resources needed to develop and implement high quality plans that produce meaningful results for people with disabilities.

Holburn (2002) observes that in developing a plan, the focal person's needs must be negotiated in light of the potential competing priorities such as health and safety, availability of resources, and what others want for the person. Similarly Kilbane & Thompson (2004a) identify possible conflicts in achieving person centred goals and managing duty of care issues and Medora & Ledger (2005) note tensions regarding issues of consent and appropriate staff roles.

Duffy (2004) discusses the tension that exists between organisational planning and individual planning. Planning for what one person desires may conflict with what others

using a service may desire, or need, or with the constraints of what is available. Duffy sees PCP and system planning as tensions that can be managed because each type of planning needs and impacts on the other. In order for the service to develop in a responsive manner it needs to know the individual needs and wants of service users; and in order to plan for the individual, people need to know the organisational constraints that exist in order to work to overcome them.

While organisational and system issues appear very significantly as barriers, the outcomes of PCP demonstrates that barriers can be overcome (Robertson et al, 2005; Mendora & Ledger, 2005; Johnson, 2007; Robertson 2007a; Parley, 2008). Rouget (2003), commenting on the implementation of person centred approaches in Australia, cites examples of innovative solutions that have been developed through alliances between people with disabilities, their supporters, and disability support organisations. She notes:

> *there has been no need to 'wait' for the whole system to change to create small pockets of innovation. However what has been most important for those seeking innovation is to be clear on the range of guiding ethics and principles for living one's own life as part of the community. (p. 3)*

Leadership/staffing/skill development

Cambridge & Carnaby (2005b) note that a key factor in effective PCP is the presence of competent and skilled organisations to support the planning. In light of the many barriers that face the achievement of PCP, positive leadership at all levels is seen as an essential component. Johnson states that "leaders need to be able to help staff acknowledge and handle the contradictions and conflicts in their role" (2006:34). Further, O'Brien (2004) states that PCP only becomes a vehicle for organisational change if staff and management use what they learn by participating in PCP processes; and become conscious of the gap between their current practices and the person centred guiding principles. In addition, the capacity of service personnel to deliver creative and individualized strategies as they move away from traditional care models to more person centred approaches needs to be developed and encouraged by strong leadership (Parley, 2008).

The changes in the power balance as power shifts to individuals and their families may also cause difficulties for many professionals (Kilbane & Thompson 2004b). The challenge for professionals is to relinquish their role of 'expert' and 'fixer' and move to a role of using their expertise to work with the individual and the individual's supporters (Kilbane & Thompson, 2004a; Kilbane, 2008; Marrone, Hoff & Helm, as cited in Holburn, 2002).

Mansell & Beadle-Brown (2004) observe that ultimately it is the work of support staff that make plans a reality and they recommend that staff training emphasises action that makes tangible differences in the lives of people with disabilities rather than focusing on the planning system itself.

The development of competent personnel to facilitate and participate in PCP requires thoughtful education and training programs (LeyRoy et al., 2007). Research has demonstrated that short one-day didactic training programs are not sufficient to enable participants to demonstrate PCP skills (Hagner, Helm & Butterworth, 1996; Heller et al., 1996 as cited in LeRoy et al., 2007). This research is supported by the view of Felce (2004) that short bureaucratic training is doomed to failure.

Demonstrating the considerable input that may be required to develop quality person centred approaches, Robertson et al. (2007b) describe the development work that was required for the introduction of PCP in some areas in England. That development involved assistance to develop strong policies and procedures to support PCP and training and support, over a two year period for both facilitators and managers which involved 20 days at each site.

LeRoy et al. (2007) trialled an extended training program that involved augmenting didactic instruction, with role-playing and mentoring, over an extended period. The program included two to three curriculum sessions; guided practice in conducting PCP and independent practice. The results of their training program demonstrated that participants developed good skills for structuring meetings, interpersonal skills and planning strategies, however

had more difficulty incorporating creative, person and culture specific resources and strategies in planning processes. They surmise that training programs must also address critical thinking skills to enlist non-traditional supports and think beyond discipline-specific or institutionally available solutions. Similarly Stalker & Campbell (1998) emphasised the need for comprehensive training for facilitators and the use of mentoring of facilitators over an extended period of time.

The skills and the values base of individuals whose role it is to facilitate the development of person centred plans, and the logistics of ensuring they are available when needed has been an issue in some cases. Callicott (2003) notes that PCP requires the use of skilled facilitators and Holburn (2002) reports difficulties when facilitators act as if they are conducting conventional planning meetings and stresses the importance of adequate training for facilitators.

Robertson et al. (2007a) found that by far the most common reason for the failure of a person centred plan being implemented was problems related to facilitators, such as facilitators leaving their position or not being available. When plans had not been developed participants in their study cited lack of time and staffing issues as reasons. Similarly Routledge, Sanderson & Greig (n.d.) note that intensive initial training will be needed for facilitators and that this will need to be followed up with ongoing supports and strategies to support their work.

Gregson (2007) discusses the difficulties that may occur in relying on one person as the key component in making the planning process happen and difficulty in recruiting people to the facilitator role. In Hampshire the approach was therefore taken to train the whole planning circle rather than people specifically as facilitators. This resulted in all members of the group becoming skilled in the various tasks.

Implementation issues

Failure to translate plans into action is a common issue in PCP processes (Mansell & Beadle-Brown, 2004; Routledge & Gitsham, 2004). Gregson (2007) points out the

importance of ensuring that the person centred plan is not a one-off event. Likewise Michaels & Ferrara (2005) emphasise that good PCP is really about implementation, evaluation and the day-to-day work that is needed over the long haul. Implementation needs to work to manage immediate needs and continue to work towards the longer term goals.

Robertson et al (2007a) cite some of the problems in the implementation of PCP which include:

- Goals remaining unmet (Coyle & Moloney 1999, Dumas et al 2002)
- Goals being limited to options previously available to service users (Coyle & Moloney 1999; Dumas et al., 2002)
- Goals in more ambitious or contentious areas such as sexuality not being met (Coyle & Moloney 1999; Dumas et al., 2002)
- Goals not corresponding with preferences assessed by alternative means (Reid et al, 1999).

It is important that energy is put into ensuring that the plan is a continuous evolving process with sustained efforts required from people at all levels to follow the planning phase with action and ensure that plans continue to evolve as changes occur. Holburn (2007) also states that breakdown in the process may occur when insufficient emphasis is placed on the planning and investments that are required in following up the initial planning stage to implementation.

Mansell & Beadle-Brown (2004) cite one explanation for failure in implementation as insufficient understanding of PCP but note that another explanation may be lack of resources to achieve goals and lack of staff skills.

Systemic and funding issues

Whilst the previous section highlighted the significant issues and careful planning that needs to be undertaken by organisations that wish to move to person centred approaches, issues relating to the entire disability service system, government leadership and initiatives also need to be considered. Medora & Ledger state that "PCP cannot exist in isolation, only

within the broader service system and policy context locally and nationally" (2005:164). Routledge & Gitsham (2004) and Mansell & Beadle-Brown (2004) observe that a move to person centred supports requires changes to resource allocation and resource management. If PCP is to achieve its goals of providing control and choice in the lives of people with a disability, it will need more than finding out what is important to them. It will require the plans to be linked to the ways in which resources are allocated and used. Dowling et al. (2007) argue for the need to restructure funding arrangements to provide more control to people with disabilities.

Mansell & Beadle-Brown (2004) argue that funding should be based on an assessment of individual needs rather than whole service funding and Felce (2004) states that PCP needs to be developed alongside restructuring of policies and practices to individualize the authorizing, contracting and financing of supports for individuals. In this way "strategic planning provides a resource climate within which PCP and decisions making can take place" (2004:28).

Some writers also caution that care needs to be taken to ensure that PCP, with its focus on natural supports, does not mask the social costs of insufficient public expenditure on supports for people with disabilities (Mansell & Beadle-Brown, 2004; O'Brien J, 2004). Mansell & Beadle-Brown advocate that national policy needs to set the expectation that personal goals would be resourced and achieved and that performance measures should then focus on quality of plans and implementation rather than numbers of plans.

In England, the widespread adoption of PCP across service systems, which has largely been led by the Government through the White Paper 'Valuing People', has resulted in considerable debate and discussion about the widespread implementation of PCP (Mansell & Beadle-Brown, 2004; Kendrick, 2004). The concerns lie not in the process of PCP per se, but that the widespread adoption of PCP will frequently be misapplied and issues and problems that are encountered in the process will not be attended to. Felce (2004), states that the issue is not whether PCP is effective, but how to adopt widespread implementation without degradation of the process.

Kendrick (2004) also discusses the contradiction that occurs if PCP is adopted in a prescriptive manner that mandates that everyone must have a person centred plan, when the values of PCP are underpinned by respect for individuality and choice. He also cautions against two things: viewing PCP as a panacea for all the difficulties faced by any individual and secondly, underestimating the difficulties encountered in PCP.

O'Brien & Lyle O'Brien caution that while PCP emphasises the importance of 'listening' to the desires and needs of the focal person, it is likely that the political stand and views of professionals and others involved in the planning process will shape the listening and problem solving. The example they provide is that listeners who are committed to inclusive workplaces hear the desire to find a job in a local workplace; listeners who are committed to providing sheltered workplaces, hear the desire for some improvements in the sheltered environments. This emphasises the need for participants to have a deep understanding of the principles that underpin PCP such as the focus on social inclusion and community participation. Well executed, though, the PCP process "can energize inquiry, understanding, and creative action on whatever areas of agreement may emerge, but only if the existence of the conflict and its stakes are openly acknowledged and explored" (pp. 3-4).

O'Brien & Lyle O'Brien, also point out the importance of being clear about what resources are available to the planners in developing a plan. This includes social resources such as committed family members, networks of contacts and allies; and service resources such as funds, service capacity and skills. It is not that the plan needs to be limited to what is available but rather that identification of resources makes clearer the issues to be dealt with in making the vision of a desirable future a reality.

> *"Proficient PCP requires investment in the kind of long-term, regular face-to-face sharing (of activities, stories, and questions) that builds communities of practice that are able to create knowledge and skills relevant to today's opportunities and challenges" (Lyle O'Brien & O'Brien, 2002:5).*

However Mansell & Beadle-Brown (2004) raise concerns that in the absence of individual planning not being legally mandated, the scope for redress if aspirations are ignored or

subverted is very limited and that this will be a difficulty in ensuring system wide implementation of PCP.

The gap between what is currently available from disability service systems and what is needed to work in a person centred way is often large. Difficulties noted in England include:

- The bureaucratic processes and systems that stifle creativity
- Priority place on targets and statistics rather than outcomes for the individual
- Conflict between roles such as gatekeeper of resources
- Limited financial resources to implement PCP
- Eligibility criteria
- Confusion over whether service managers should lead planning, assist in planning or whether planning should be separate from services
- Conflicts between duty of care and person centred approaches
- Pressure between producing good plans and ensuring that everyone has a plan (Johnson, 2006).

Similarly Robertson et al. (2007a) found that system issues such as limited choice of day services, waiting lists, limited housing and lack of accessible community activities were significant barriers to the implementation of plans.

Kendrick (2004) notes that very few services and service systems that adopt PCP also foster the capacity for supports to be redesigned to better suit the needs and requirements of individuals. Funds must be 'un-bundled' and resources used in new ways and this must be done at a system level.

Working with Cultural and Linguistically Diverse (CALD) communities

There is a significant body of literature that addresses PCP and also significant literature about working with people from culturally and linguistically diverse communities (CALD). There is little literature about the application of PCP with CALD communities and the literature search did not reveal any literature specific to PCP and indigenous communities.

There was no literature available for this review that specifically discussed the application of person centred approaches to Aboriginal and Torres Strait Islander people.

Cambridge & Carnaby (2005b) note the importance of cultural sensitivity in developing successful person centred plans. Callicott (2003) has examined the relevance of PCP to CALD communities. She views PCP as an important way to address the disadvantage and risk of unequal representation in traditional service meetings by bringing to the fore the person and their family's aspirations and what is important to them.

Hasnaim, Sotnik & Ghiloni (2003) demonstrated successful outcomes in using PCP approaches to develop employment outcomes for people with disabilities from CALD communities. They point out the importance of being aware of the extent to which the norms and values of society are primarily mainstream and middle class in nature may not be valued by people from other cultures. For example the idea of independence which is a deep concept in Western societies may not be valued by people from other cultures. Such taken-for-granted concepts may hinder the involvement of many individuals and families from CALD communities. Hasnaim et al. believe that PCP approaches are able to assist in understanding cultural factors and the variety of the factors within and across cultures.

Hasnaim et al. found difficulties in explaining the concept and benefits of PCP in engaging people from CALD backgrounds. They found it difficult to translate service terminology and jargon and that the concepts themselves had little meaning to people from different cultures. These difficulties were addressed by using real life examples and by spending more time that would normally be needed. Hasnaim et al highlight the need to gain insight and sensitivity to the beliefs, practices and expectations of the person with a disability, their family and their community.

Conclusions

This review of the literature points to a number of significant issues to be considered in the development of resources to facilitate the development of a person centred approach.

The literature review has demonstrated that person centred approaches can achieve significant outcomes for individuals with disability. Positive outcomes have been evident through large scale studies, small studies and individual reports.

The literature has highlighted that there are fundamental differences between person centred approaches and traditional individual planning. It has also highlighted that problems can arise when IPP approaches are reinterpreted with the rhetoric of PCP without the necessary changes in underlying thinking and practice.

The implication for the development of resource materials is that they will need highlight the fundamental differences between PCP and IPP approaches such as power sharing; emphasis of what is possible and not just what is available; and fostering of community relationships, inclusion, dignity and respect.

The literature has highlighted that there are significant barriers to the successful development of person centred approaches that need to be addressed. If person centredness is to be achieved attention needs to be paid to:

- Developing a deep understanding of the complexities of person centredness
- Fundamentally changing organisational structures and processes
- Ensuring strong leadership to support the development of person centred approaches

- Ensuring that people with disabilities, families and staff are well supported and educated

- Ensuring that systems and practices are in place to achieve the implementation of person centred initiatives

- Developing commitment, leadership, and support at a systemic level to facilitate person centred development by the service sector and community*.*

The implication is that, given that the literature highlights organisational and systemic issues as the major factors that either support, or inhibit, the successful development of person centred approaches.

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