Shifting Shapes of Support
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The Community Living Association’s story of person centred planning and creating increased opportunities for self directed services.

Acknowledgements

This work is dedicated to all the people involved with the Community Living Association (CLA).

The commitment to become a learning organisation and employing a knowledge worker would not have been possible without the disability industry seed grant made available by the Disability Services Commission. Engaging a dedicated worker to review and monitor CLA’s practices against contemporary evidence based research on person centred approaches has strongly influenced the commitment to greater self direction for people supported.

Disclaimer

The people of the Community Living Association Inc (CLA) do not claim to be experts in Person Centred Planning (PCP), co-production or self directed services. The following is based on records, recollections and reflections of ways of working with people with disability that lead to their greater happiness and satisfaction. In balancing between the need for independent thinking and innovative practice, and not trying to re-invent the wheel, we have by way of necessity carved our own way forward rather than replicated what others have done. We have drawn freely on the relatively large amount of information that already exists about Person Centred Planning (PCP) to stimulate thinking and generate motivation and ideas, and throughout the publication due acknowledgement is given. What remains is the recounting of an individual organisation’s journey, including both the creative story and observable experiences of constantly striving to become more person centred in our service delivery practices and allowing for greater self direction for the people the Association exists to serve.

Terms and Acronyms

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Introduction
From humble beginnings in 1991 the Community Living Association Inc (CLA) has been on a journey of discovery and learning with the people the association provides a service to. At this point of convergence of a number of different waves of change across the disability sector, it is appropriate and timely to share what we have learnt along the way. In the quest to increase the effectiveness of support services and maximise the life outcomes for the people supported, particularly the degree to which people own and participate in decision-making, the CLA has discovered and developed a range of innovative measures that revitalise and enhance person centred service delivery. We have learnt that authentic person centred or self directed service is not possible unless the organisation is person centred and this permeates all aspects of delivering the service. This includes the day to day support provided to people, the recruitment and retention strategies for staff, the administrative systems, the policy development and review cycles, governance, models of support, financial and budget planning and management, risk management and most importantly the values and principles applied to all relationships and interactions within and externally from the organisation.

Though it takes a wandering path, this book is about person centred service delivery and a move towards increased opportunities for self directed services. That is the practical application of ideas which challenge the traditions of institutionalising people and thereby depersonalising them. This way of working with people has been around since the 1980’s and is based upon principles of upholding the right of people with disability to live rich and fulfilled lives. There are however, still a host of barriers to overcome before understanding and implementing person centred practices within an organisation with the integrity it demands.

Person Centred Planning is one of the key tools adopted by individuals and services when working in a person centred framework. The original ideas on person centred planning are said to have emerged in Canada and after a period of development there spread rapidly through America, the United Kingdom, Europe and eventually Australia. As is often the case, as the ideas spread, they evolved and were adapted, opening up a familiar gap between theory and practice. This is not surprising and was not unexpected by those pioneering in this area. Many writers and teachers of person centred planning have warned about the challenges that the implementation of such an approach would mount for service providers. In many settings there remain multiple, multilevel factors that prove incompatible with and resistant to some of the ideological prescriptions of person centred planning. In practice these factors force modifications which threaten and corrupt the original ideas and lead to failures in sustaining the original promise and meaning of person centred planning. Relatively recent reports of these shortcomings indicate the need for a deeper and more constant consideration of the whole range of constraints on the practice of person centred planning and service delivery.

The story of the evolution of the CLA is made up of the stories of the individual people supported, interwoven with the steps and stages of the broader changes in the organisation. These individual stories make up the main threads in the learning process, providing both focus and inspiration to keep building upon our knowledge in person centred practice.
This introduction of Person Centred Planning begins by revisiting a couple of well known pieces of information or concepts. One shows us the great distance there is yet to travel on the road of supporting people living with disability. The other, hopefully, reminds us that although some steps may be small and may have to be repeated that people can and should live rich, fulfilled, active lives that they are in control of.

It was stated in the introduction that one of the aims of this work is to bring some inspiration to the work of person centred service delivery - a big ambition given the degree of impact on the lives of people with disability that emerged from the original practitioners. The first of our sources of inspiration does what many great ideas offering a different perspective do... it turns the whole world upside down.

First conceived in 1943, Maslow’s hierarchy of needs was developed to aid understanding about what humans needed and the order of priority in meeting those needs. Though this order of needs has been challenged by others over time, the idea survived relatively intact until 2004. Since then people have been realising that in developed countries, the priorities of the pyramid of needs had been radically changed. In fact, it is upside down.

Anthropologists and psychologists now all agree that human beings are by definition creatures of meaning and value. That is, the need to self-actualise has precedence before all others. For most people self-expression in everything has become the order of the day. People are busy creating their world and as much of it as they can access and control (with or without conflict) to reflect who they are. It is as if all the conscious or unconscious strategies are part of an overall strategy to meet the need to create the Self.

This is a general statement about a wide-spread social trend illustrating a changing pattern in the focus and behaviours of people in the mainstream. There are of course still groups of people in many countries for whom food, shelter and safety are primary and immediate concerns. Some people with disability belong to these groups; and they are certainly present in the groups of people who are being more marginalised in the community and for whom respect, friendship, belonging, intimacy and many other needs dependent on the interaction with others, are largely unmet. Even in these groups people experience more happiness and satisfaction if they can meet their higher needs. Failing this they are likely to become sick and close down to life, maybe even die sooner, or at the least live without full vitality.

Consideration of Maslow’s hierarchy, albeit the upside down version led the staff at CLA to question:

Are our current practices narrowing the gap in relation to self-determination, opportunities for self-development and self-actualisation? Or is this only considered for some people, and just for those with whom it is easier?

What do we do in supporting people to learn about themselves in order to acknowledge, understand, communicate, prioritise and strategise the complex range of human needs we all embody?

One of the features of PCP is that people’s ownership of their lives and affairs is handed back to them or safeguarded by people other than those who are in a paid relationship with them. Interest, participation and motivation are therefore key ingredients to successful planning. People may require opportunities and learning in how to effectively communicate their needs, wants and feelings and to be able to participate in planning processes and service responses that impact on their daily lives.
Person Centred Planning
A Brief History of PCP

In 1969 Nirje published his Normalisation Theory, the first to challenge many earlier assumptions about the treatment of people with disability, including misconceptions about people's development potential. The focus on acknowledging and maximising people's gifts and abilities seems to go hand-in-hand with the earliest ideas of improving quality of life.

Social Role Valorisation (SRV) which Wolfensberger drew out of the Normalisation Theory, and with which he began to guide an application of Nirje's ideas, set out to redress the wounding inflicted by outdated practices. He did this by asking questions like: “Who is this person?”; “What do they need?” Those involved in these early efforts which laid the foundations for PCP acknowledged the right of people to control and direct their own lives, and supported them to take on valued roles in their communities. This remains one of the central concerns of SRV. The early practitioners also activated for the closure of large residential institutions. That period reads as one of great excitement, challenge, hope and change. It involved people and groups from a wide range of sectors in the community, including lawyers, politicians, self advocates with disabilities, families, church groups, medical professionals and others.

As the PCP family tree overleaf depicts, different streams of practice emerged in the next generations of these ideas. Each of the four groups of originators following Wolfensberger developed its own approach with a quite different focus and different names. Individual Service Design, the model developed by Jack Yates as a means of guiding the practical application of SRV, added a third question: “How do we get this person what they need?” Personal Futures Planning incorporated broader, more macro focussed ideas from planning to development and sought to engage people in challenging the obstacles and constraints in the systems surrounding the person. MAPS was created in 1989 to support the inclusion of children with disability in schools by fostering shared understanding in the group supporting the child. Essential Lifestyle Planning created by Michael Smull and Susan B. Harrison in 1992 formed the basis of plans to support people to move from institutional care to community living.

People within the PCP community further developed their ideas by incorporating innovations from outside their circle. Two are most notable because their ideas remain central to how PCP is practiced now. The idea to base planning around an individual’s hopes and dreams - the focus of Emelie Cullis and Bertha Young at New Hat in New York is now a central element in the PATH & Personal Futures Planning models. Graphic facilitation methods; whose origins seem obscured by history but whose ideas and tools were widely applied and adapted; are now so central to a number of approaches that facilitator training in these approaches emphasises the development of these skills.

A number of the people in this original community of practice travelled far and wide. For example, publications by Beth Mount, one of the originators of Personal Future Planning along with John O'Brien, Marsha Forrest & Judith Snow - and the Circles of Support concept, have been translated and used to teach throughout Latin America, particularly in Mexico, Brazil, Uruguay, Argentina, Poland, China, Japan, Russia and Spain, not to mention the United Kingdom and Australia.

The ideas and impact of PCP has so fired the imagination of people at all levels in the United Kingdom that this approach has become the standard in human service organisations in both government and non-government organisations.

“Valuing People”, a White Paper issued by the British Government states that “all people with learning disability who want a person centred plan should have one”. However, the experience in the UK is not without criticism and it would appear that service providers have faced the same challenges as CLA in implementing PCP in an authentic way. Some commentators suggest that if not well understood PCP can become a paper driven exercise that serves to meet reporting requirements rather than the needs of the people they are developed for or with.

Communities and organisations in North America and Canada remain rich and fertile in developments of PCP. Some organisations and communities continue to channel the ideas into other areas of human service; including mental health, aged care and youth work; persevering to push the boundaries of service centred approaches, as well as creating and disseminating tools and resources for influencing thinking and practice all over the world. An Internet search today results in close to a million possibilities of sites offering information and resources.

There is now a somewhat confusing array of terms and titles used in PCP. Some appear to be offering something new; others are clearly variations of the old. As with the earliest, there does seem to be some distinctions between the place and purpose of some. For example, methods such as “Circles of Support” and “Microboards” are being adopted as approaches to support more family - led efforts to manage and improve relative’s lives. “Optimal Individual Service Design” seems to be about organising values-based training for staff at different levels in service provider organisations, and “PATH” has been found useful in service organisations for developing community living plans.

PCP has been initiated in Australia by various innovators in diverse places in the Eastern States. Over the past three to four years in Western Australia there has been an interest and practice in non-government organisations, largely influenced through connections with the United Kingdom. These have been providing consultancy and training in non-government sectors involved with disability, primarily in the use of the MAP and PATH models of planning. In the government sector the Community Living Plan framework, initiated by the WA Disability Services Commission, has been used to focus on promoting person centred and self directed approaches.

More recent research and approaches have led to a greater emphasis on self directed services; that is giving people greater control over the development and ongoing nature of the supports they receive. This includes a reduced focus on paid support and increased opportunities to build upon informal and natural support networks, with an overarching principle of a shift in control over the services provided.

SRV theories as they are applied in the lives of people with disability emphasise a fundamental principle: everyone determines their own lifestyle and personal affairs. This includes the acknowledgement that people have a right to varying degrees of need or support to do this. Those who first developed it used the term ‘person centred’ to stimulate a change in thinking and practice, in order to ensure that those providing the necessary support did not continue to do this in a depersonalising or service centred way. To be person centred means that it is imperative that all aspects of support are reflective of the needs, interests, wishes and preferences of the person being supported.
More recently critics have discounted the principles of SRV stating that the concepts of increasing valued roles is limiting and based upon outdated ideas of social deviation. At CLA we have retained the aspects of SRV that lead to better life outcomes for people and those that can be easily understood and applied by support staff.

Going one step further, the central principle in PCP is that a sustained, systematic approach is required to ensure the improvement of an individual’s quality of life. This whole process is person centred in that it is not only reflective of individual needs, but that the person’s opportunity to control and own the process is maximised. As much as is possible, the supported person and their family members, as well as those in other close relationships with them, participate in and influence all decisions about the goals, strategies and agreed actions to achieve quality of life outcomes.

John O’Brien states that this conditional phrase “as much as possible” was included in the original ideas of Nirje and Wolfensberger, to be a motivator for continued learning and the effort to expand what was possible both for people and organisations. The originators and early practitioners and writers communicated the potential or promise of PCP to be a life changing, life improving practice for all involved, and that it could be extended to all people with disability. They were also aware that fulfilling the promise of PCP would require a paradigm shift for service providers, given that they are traditionally service rather than people oriented. This is especially the case where there are larger numbers of people involved, and true of all human services organisations, not just those of the disability sector.

In 1997 Sanderson et al reminded us in their publication about PCP about the need to make changes to our collective thinking and behaviour in order to learn about planning with people, so that people are at the centre of it all. If the one million or so internet sites providing information, tools and techniques for engaging people in this process of rethinking and changing practice is anything to go by, it could be fair to say that the last decade has seen a lot of change in this regard, in thinking, communicating and writing, as well as in practice.

In many fields there has been such a proliferation of models as to create what has been called ‘jungles’ of theory. What a great image! Here we have jungles of knowledge, overwhelming and seemingly impenetrable; posing a massive challenge to anyone new to the field to track down and sort out what might be applicable and effective in their specific day to day situations. In relation to PCP, though there are a relatively small number of models to choose from, there is also an overload of information. In this sense we could be heading towards the theoretical jungle stage. As stated earlier, there are also concerns that some of the current applications are in danger of being quite far removed in integrity from the original principles. Getting lost is one of the perils of entering a jungle. It is also possible to encounter seemingly impossible barriers which may lead to diversions from the original course or intention.

In exploration of this in relation to PCP, a number of writers and reviewers have identified a range of problems and barriers and also noted factors known to increase effectiveness. An organisational culture that focuses on staff needs over the people being served, top down management styles, tenuous relationships between planning and outcomes and a lack of opportunity for self direction all contribute to person centred planning losing it authenticity and effectiveness.
Foundations and Innovations
Community Living Associations were established in regional Western Australia in the early 1990's and were a direct result of the work of Local Area Coordinators (LAC's) from Disability Services Commission, people with a disability and their families and other local champions. They developed services based upon brokerage models giving people greater control over the support they received, the timing of that support and who provided it. This reform in the delivery of services to people with a disability in regional Western Australia in the early 1990's formed part of a world wide trend towards more individualised, personalised and community based support. The vision was to develop a more inclusive community by enabling people with a disability to purchase in their own supports and have access to generic services. Ensuring that people remained living in their own community and did not have to relocate to larger regional centres or the metropolitan area to access the services and supports they required was fundamental to the original vision of CLA.

The CLA was founded in 1991 based upon on the principles embedded in SRV. From the outset, it was decided that the support would be designed and implemented according to individual needs and preferences, with the chief principle that people would be supported to live in their own homes. At the time this approach to accommodation support represented a fresh and challenging alternative to the Group Home Model being adopted by the disability sector in WA. CLA is still accorded recognition and respect for its ongoing commitment to the principle and practice of providing people with individualised accommodation supports.

As it grew, the organisation took on the provision of support services across the range of DSC funded programs, Supported Community Living, Alternative to Employment and Intensive Family Support, with characteristic commitment and vision. In 2004, CLA added a second arm to its mission statement; that of working in partnership with individuals and organisations to identify and/or create opportunities to build a welcoming and inclusive community. The premise for change was an increased awareness that provision of direct care to individuals alone would not achieve the vision of a welcoming and inclusive community. It was understood that this may result in people living in and being visible in their community of choice, but would not necessarily create opportunities for participation, contribution and inclusion. “My Life My Community”, the organisation’s award winning community development initiative was the first of a range of programs which showcased CLA’s capacity for unique and innovative solutions to social issues. CLA has continued to uphold its commitment to provide individualised support for all people, including those who have been referred with a reputation of being too difficult or unsuitable.

Each step towards improved person centred practices seemed to highlight further barriers. The process of addressing these barriers led us to consider pathways and possibilities of supporting people in a person centred manner, regardless of their level of ability, disability, or challenge presented to the organisation in supporting them.

In the past, opportunities for social and developmental experience were not always easily accessible. Some people who had extreme and/or dangerous behaviours, and others who did participate but who also had some forms of anti-social behaviours although not necessarily dangerous, were at risk of exclusion. Others, because of poor social skills and self confidence would lack or easily lose interest in the offered opportunity. Still others have remained at risk of exclusion because their attendance is dependent on the cooperation of staff who may have misconceptions and unaligned attitudes which create additional barriers.
That being the case it gradually becomes harder and more futile to maintain interest in any element of life; consequently people lose, or do not even in the first place develop, a sense of the meaning or wholeness of their life or of themselves. This fragmented or incomplete experience of self is not the case for every person with disability, nor is it exclusive to people with disability. It is however a significant issue when supporting people to take or regain ‘ownership’ of their existence. Every person has a right to their own lives, and need not be restricted of their support worker’s or anyone else’s. These statements are not meant as criticism or to devalue all that is done and offered, but emerge from a reflection about how the lives of people with disability can be different, resulting in a strong commitment to the continuous improvement of suitable support structures. Our intention is to stimulate ongoing critical reflection, discussion and action.

Ensuring opportunities are sustained is vitally important. A lack of sustainability had been stated as a problem by people with disability participating in a survey conducted during our involvement in the Challenging Behaviours Consortium. It is possible to conclude that this lack of continuity and sustainability is a problem which seriously impacts on that person’s sense that their life is actually improving and that they have some control over it. In addition, it can impact on their ability to participate meaningfully in planning for the improvement of their quality of life.

None of these thoughts are especially new, there being many writers who have addressed these issues and the multitude of other problems experienced by people with disability every day. What was new and innovative for CLA was our group program that gave people an opportunity to learn the skills to communicate what they felt and needed. The group provided a unique and ongoing opportunity in which people could support each other to learn and practice self and social awareness. This in turn increases the meaningfulness and accessibility of other opportunities in their life, such as participating in PCP. All of this has meant that before beginning to implement the more formalised processes of PCP, CLA had already been building very substantial foundations for the effectiveness of these processes.

Interpersonal relationships are known to be pivotal in determining the quality of life of people with disability. That this is understood universally is reflected in directives about the need for improved outcomes in this area for all disability support programs. All approaches to PCP emphasise the importance of the right support people. Those that are the most effective are based on the forming of a circle of people who will consistently include and surround the person of focus. Many enthusiasts believe that the circle is even more important and effective in helping people create their own lives of quality than the plan itself.

That may be the case but rather than debate this, our concern is mainly in working with the concept of a ‘circle of support’, especially given the challenges that are faced in creating and sustaining one. It is ideal to view a group of support people as a circle, and possibly, with appropriate attitude, training, discipline and support, to hold this situation stable for an adequate timeframe so that it can sustainably and positively influence an individual’s decisions and actions. However, the real ‘shape’ of interpersonal support systems far more resembles a web (or the pattern of a network) with elements linked through different patterns and rhythms, rather than a consistent sustained relationship with all parts equidistant from the centre.

From this perspective it becomes very clear that it is the day to day connections between the person supported and others that influences the success or failure of achieving goals. We all have had some experience of when an individual with unattended issues and/or overwhelming personal needs had derailed collective efforts.

Mike Kendrik emphasises this ‘make or break’ aspect of the interpersonal relationships in disability support services. The integrity and balance of power in each one of these relationships influences whether the person supported has a good quality of life or not, and whether or not they experience ownership of all or any of the necessary elements of this.

Regardless of either the approach to PCP, or the quality and integrity of the processes, the person with a disability is often reliant on the motivation, interest, values and actions of an ever-changing ‘other’ and are often forced to wait upon the actions of their carer / support worker in order for something to occur. It is fair to say that the person with a disability usually experiences less power in the relationship than the person they happen to be with, and that this can be the case whether that person is a friend, family member, paid worker or a complete stranger.

Much of what is practiced in relation to evening up these relationships has to do with educating others in skills and competencies related to being with and communicating with people with disability. There is an increase in giving attention to and resources for supporting staff and others involved to adopt person centred values and attitudes, and to redress the imbalance of power in these relationships in order to enhance quality of life. Sometimes some of the limitations of the effectiveness of PCP can come from the person being supported, and may persist regardless of the model or shape of the planning and the extent or composition of the support team, which then leads to failure, as has been reported.

One of the innovations that CLA adopted to address these imbalances in relationships was to set up the Stand Up for Yourself and Buddy Bunch groups. Although the format has recently changed the focus is on the development of interpersonal and interpersonal knowledge, skills and confidence for adults with disability in an environment in which they can more easily interact. Not surprisingly it has also increased the interest and motivation of participants in a range of areas, including participation in person centred initiatives, and has shown potential as a forum for consolidating and communicating opinions and wishes about support arrangements outside of formal planning.

The program was featured at the annual ASSID conference in 2007 and 2008. What follows is a modified copy of an article about the programme which was written for different publications following the 2008 ASSID conference.
Meeting the Need to Belong
An Experience of a Unique Group Program in WA

Halfway up Maslow’s hierarchy of needs, “belonging” is the most frequently cited “need met” in a unique or group program developed by Community Living Association in Albany WA. The program emerged in stages and grew out of the organisation’s commitment to find and use best practice approaches to improve quality of life for people who had been difficult to support in the community. Its aim is to give people the opportunity to support each other to learn and have new experiences, especially in the areas of self awareness and social interaction.

What we did:

Initially, in September 2005, a small group was set up for people with intellectual disability to learn Nonviolent Communication (NVC) an internationally recognised and applied communication and conflict resolution approach. This approach had already been introduced to staff in the organisation. This weekly group focussed on teaching people to use a four step process: say what happened; identify and name feelings triggered; understand and communicate what any underlying needs might be; and figure out what they may need to ask of others or of themselves to have these needs met. People were given individual support to complete each step and then progress to the next. To make the learning accessible and inclusive, we used Softpix Alternative Communication Tools and changed all the resources for identifying events, thought, feelings and needs into pictures.

In group discussions people were supported to identify similar experiences and events, educated about the range of needs and feelings involved, and encouraged to share the similarities and differences of all of these. Early outcomes were very exciting and clear, especially when “belonging” was identified by group participants as a significant ‘need met’ by the group.

A second group, similar to the first, was started for people with disability who had missed the original NVC training. A third group was created for people who were cognitively less able with the aim to stimulate self awareness, emotional expression, and cognitive and social development. All three groups were sustained for four years, with people able to choose the group which suited them best. Many people belong to two groups simultaneously and a small number attend all three. After four years it was decided to change the format of the groups as the participants were no longer receiving the same benefits due to the level of skill accomplished in expressing their needs and asserting their opinions. It was agreed to pursue other interests and community based activities chosen by the participants, thereby retaining the sense of belonging developed and opportunities to maintain friendships.

Building upon the learning from the ‘Buddy Bunch’ and Stand Up For Yourself Groups CLA is now embarking on developing the skills of the participants further. We aim to set up a working group which includes the participants from the group program and others to help with policy development and review.

Results:

The founders of the group did not set out initially to collect data, but simply to provide opportunities for new experiences and to support participants learning and personal growth. This has lead to people experiencing a greater capacity for and more confidence in making changes in their life. For example, one person was able to express an over riding feeling of sadness that permeated her whole life because of her estranged relationship with her family. Being given the opportunity to express this clearly and safely opened up opportunities for her behaviour to be better understood by support staff and others and for more appropriate responses to be developed. Knowing a person is estranged from their family is one thing, but hearing from them the daily impact of this changes the way the service responds and defines support needs.

Another participant in the group was able to express her feelings of being “let down” by support staff when they did not support her daily routine, which helped her to feel safe. Learning to express this to management and support staff and requesting how she would like support provided was an important step in becoming more self directed and having control over her own life for this participant.

For one participant there was mixed feelings expressed about her sister getting married. On the one hand she was happy but also expressed feelings of jealousy and wanting close and loving relationships in her life. Identifying these feelings led to more meaningful planning and strategies to achieve this goal, which was about increased relationships with people who were not paid to be in her life.

For members participating in the third group there were some significant changes reported in other areas, such as the ability to make eye contact, tolerate the presence of others, give and receive touch, contribute their own ideas, an increased range of movement, more effective expression of feelings both positive and negative, increased use of language (including AAC) to express feeling, the ability to identify between needs met and needs unmet, the ability to initiate interaction and manage self disclosure and to regulate socially inappropriate behaviours.

Adam is an example of a person who has undergone considerable personal growth from his involvement with the group. For many years, whenever present in a group setting, he would be found pacing alone with his chin on his chest, not responding to any attempts at contact, whilst now he looks up at others when they speak to him, contributes and engages in activities and recently started to initiate interactions. We have discovered that there are other researchers and writers who validate that participation in such a learning environment is more likely to lead to more effective learning for people with intellectual disability.

Michael Small says that what is worse than not listening is listening only once. Other things that could be worse than not listening, include listening only to those who can use words; listening but not really hearing; listening but acting (or continuing to act) as if you haven’t heard, and failing to listen, hear and act on what has been ‘said’ before by others, or by the collective voice of people with disability.

Changing the way and how much we listen and hear demands ongoing reflection, discussion, action and resources. Hearing people’s individual voices and learning to listen to those who have high communication needs, calls for the considered use of quite specialised skill. Flexible and individualised approaches that are highly sensitive and responsive to the all the nuances in the communication feedback loop and resulting power differences are imperative.
In the busyness of the logistical and practical aspects of providing support, it is easy for people’s actual needs concerning this to be overlooked. Many of the causes or triggers for challenging behaviours have been found to be caused by ineffective communication and corresponding imbalances in power, as are many of the failures in PCP.

CLA is not the only organisation to state that effective communication is synonymous with effective PCP. In some places in the UK, the Total Communication Approach, which emphasises the power and place of all means of communication, is seamlessly integrated with PCP. The development, continuity and improvement in alternative communication systems are totally dependent on the sustained motivation and interest of that ever changing other in the lives of people with disability. A high turnover of both service coordinators and support staff works against this, and even more so when there is no documented plan. A contributing factor is the lack of access to expertise consultancy and training in methodology; therefore these concerns are necessarily a central focus of PCP.

From its inception the group program has provided some great opportunities and challenges in learning to listen. An important thing to be ‘heard’ by the organisation was that people in the first learning group enjoyed themselves, and that they wanted to continue to meet and interact with their peers with disability. The challenge was to accept what people said, that is they wanted to go against the practice of individualising support. Meeting, having fun and being supported to communicate with others with similar experiences generated a sense of belonging for many and was a novel social occurrence, especially for those who have no family or family bonds.

Isolation and loneliness which increases rather than diminishes as people get older, has been repeatedly reported as a common experience for people with disability. Efforts to share our ideas have had a mixed response however, and have sometimes been met with criticism and rejection on the grounds that it was contrary to the aims and practice of maximising the inclusion of people with disability in community life. Nevertheless, the CLA has continued to support and extend its group program and to share these ideas with others.

It seems that, for the group participants, the program, as well as providing space and support to experience connection with others has become an important forum for continuing and extending the experience of being heard. Due consideration is given to the need for confidentiality so that people can continue to feel safe even in expressing their most negative thoughts and feelings. Participants are also supported to find ways to let their needs, feelings and thoughts be known outside the groups. The emerging information and opinions are made known to coordinators and managers in the organisation, in turn challenging their ability and willingness to listen and respond. New processes and practices emerge as this feedback loop becomes stronger and more vigorous. As will be seen later in the publication, some of these are designed to support coordinators and other staff to check the assumptions that underlie current practices, which may inadvertently be diminishing quality of life and overlooking opportunities for improvements thereof.

The program does not stand alone but is part of the broader approach to supporting people in maximising the opportunities that are available in the community, as well as working to open up new and different options at the level and pace that suits each individual.
Improving and Sharing Knowledge About the People CLA Support

“This is Who I am”

Similar to all disability support organisations, the CLA gathers, stores and shares information in many ways for a variety of purposes, including meeting individual needs of people supported, staff, employers and benefactors. Poor systems of information gathering and sharing act as a barrier as people may not be fully known or understood, staff may view their role as one of care rather than empowerment and the teams of support surrounding people may not be connected in a shared vision of what is possible for the person. Four main points and purposes have been identified in which personal information is gathered and/or shared at CLA.

Firstly, information is gathered at the point of referral, although this can be limited. As funding applications are submitted or supports are planned and implemented additional information is required from the person and or significant others to enable appropriate supports to be developed and resources secured. Some of the information required is demographic and assists the CLA to meet annual reporting requirements to funders.

Following on from this the Association gathers information that enables the support to be personalised and self-directed. The development of personalised profiles as opposed to assessments of need represented a new concept and practice at CLA when this was introduced in 2009 and is possibly the most important first step in initiating a person-centred plan. A personal profile that captures the essence of the person and covers a range of themes rather than specific closed questions about ability or lack of has an immediate impact on how the person is viewed by others. Further, it assists support staff to engage with the person on a holistic and human level and have a greater understanding of the key influences that have shaped the persons life.

The third point at which information is gathered is when a personalised introduction is developed. This is to allow people to introduce themselves to others and have control over what information is shared about them and the format for this to occur. Having a personalised method of introduction requires variation and choice for each person, including options for change and updating as each person grows and develops new skills and interests, or as their life situation changes. This introduction plays a dual role of establishing relationships with new support staff and developing a shared understanding of their role in the person’s life and giving the person control over what and how information is shared about them. It can also serve as a learning tool for staff and in some instances includes power point presentations that act as a comprehensive step by step guide to provide the highest quality of personal care for people with high support needs. In addition to achieving improved health and well being outcomes for people these introductions ensure compliance with OSH and other governance requirements.

Finally, the CLA collects and stores information whilst collaboratively developing person-centred plans that offer ongoing review of goals, dreams and strategies. It is acknowledged that not all people will choose to be involved in formal planning processes, in which case support will be provided with person-centred approaches as the underpinning values base. CLA works to maximise people’s involvement in planning and achieving goals, and continues to refine and improve systems and processes to document, record and report planning, strategies and outcomes. The documented and stored information is then an accurate and valid reference from which to compile reports on the outcomes of service delivery.

Though the aim of this particular project was to embed the principles of person-centred approaches into the collection, and the sharing of information there is an obvious continuance to other places and times where information about people can be gathered, stored and shared. The starting point for this project was the engagement of the people supported, along with their close others, in opportunities to meet with a project worker with journalistic skills to document their life stories. This information was then written down in a format that gave greater insight into the person, their cultural beliefs and practices, their strengths and their support needs. Making this information available to the relevant service coordinator and support staff, especially those who are new, ensures that information shared and acted upon is current and congruent with the way in which the person and those who know them choose to view the life and purpose of the person.

Building upon this CLA set out to maximise each individual’s control over their personal details in much the same way people without disability have. Developing a personal introduction is about working with people to support learning and skill development in a variety of different media. People can package their personal information as they want and maintain control of it and be able to engage in sharing important aspects of themselves. Some examples of how people might choose to develop and share the personal information include but are not limited to:

- Verbal introduction of themselves to a new support worker, audio, visual material, video, power point, website or other.
- Personal letter of introduction
- Life Story as a book
- Compic or Softpic pictures and stories illustrating life events
- Photo Album or Scrap Book
- Written information, poster, wall chart
- ‘Tough Book’ - a specially modified and formatted portable PC

Improving systems and introducing a person-centred approach to gathering and sharing information was anticipated to lead to the following benefits for people receiving our service, our staff and the organisation as a whole:

- Having a voice in what information is private and what is shared.
- Being involved in developing the information that may be shared.
- Actual involvement in the sharing of information about themselves with others.
- Building skills and confidence so that they can participate in future PCP activities.
- Support staff being introduced to people on a human level rather than a clinical, diagnostic or assessment of needs level.
- Support staff having access to relevant and current information that is linked to the goals identified by the person and significant others in their life.
- Preparation for reporting outcomes to funding bodies.

Poor or ill-conceived systems of information gathering and sharing result in barriers. People may not be fully known or understood, staff may view their role as one only caring for rather than facilitating or empowering. In addition, individuals of the support group around the focus person may not be connected in understanding or sharing the vision of what the situation is now and what may be possible. Belief at CLA is that time, resources, care and creativity invested at this point sets the scene for satisfaction and effectiveness further down the pathway in PCP and self-directed services.

In this next chapter, we share the stories of some of the people supported by CLA. Each story highlights the individual approach to supporting people with the ebbs and flows of life and the fluctuation in support needs at different times.
When the waitress arrives with our coffee, it turns out that she knows someone who knows Nikki’s brother Henry. It is Nikki who realised this and joined the dots for her, creating a quick, fun moment of recognition and connection in the waitress’ very busy working day - there is a Cruise Ship at anchor in the harbour which resulted in an avalanche of customers. Nikki has been living in the community since she was 12 and is one of those people who are like the social ‘glue’ who seem to effortlessly link disparate individuals together. Nikki does this conversationally, connecting the thread of their lives in simple and natural ways as we will see.

After a minute or two Nikki sees a couple, a young man and his mother, and starts up an exchange about a party on the weekend; actually more of a community event than a party; the Annual Wignall’s New Year Blues Concert. There are a few sideways references to his goings-on at the party, though he seems happily engaged in the banter.

Next Nikki gets up to go talk to a man in the far corner. When Nikki returns to the table I ask, “Who was that?” “Oh him! His dog is Boss’ father”, she says. “Who’s Boss?” I ask. “Boss is a dog!” she asserts ... “The man who is his owner ...” Nikki’s words trail off as her attention is grabbed by something over my left shoulder. “That man there!” she says bounding out of her chair to pat a large, happy black Labrador who seems as delighted to see and talk with Nikki as she is with him.

The conversation continues as they meander back to the corner and lasts quite a bit longer this time, giving my pen plenty of time to capture these moments ... having a coffee with Nikki at Cosi’s. The laughter which bubbles out seems to wrap around the place and uplift everyone within reach.

What is really important to Nikki is having her own space, to do her own thing. Though Nikki says that she has done art at TAFE before, she’s not into it right now. “I just want to be myself”. “My new house is beautiful and big and I love it and that mountain I can see from my front door reminds me of Mount Manganui.” Nikki and her family are originally from New Zealand. One of the best and most recent holidays Nikki has had was a family revisit to the mountain.

Today is not the happiest day for Nikki though. Stacey, her beloved sister and night-clubbing buddy is leaving today to live in Perth. There is a dark moment as Nikki reflects on being left behind; brother Henry lives and studies in Perth too. She thinks she probably will not be going out now as her best friend lives in Kalgoorlie and now there might be nobody to go with.

“L’s like a sister now. I have only known her since we’ve been co-residents in the last house at Bayonet Head. It was small and cramped. Couldn’t move, could hardly breathe. I love my new house and sometimes I just want to hang out with L at home. We’ve only had this house a few months.”

Similar to others with vibrant and independent spirits, Nikki’s journey to maturity and stability has necessarily involved some risky decisions and actions, and more than a few trials and errors, not to mention grey hairs, in working out how best to support her. To recount all these experiences in descriptive detail would require an entire publication on its own ... now there’s an idea... Nikki’s story. The aim of these few words is to encapsulate the mood of achievement at this stage of a long journey for Nikki and CLA, and reflect essential characteristics and qualities of Nikki herself and the CLA approach patience, flexibility, tenacity and trust in the process of self-determination.
My life is not a pile of boxes, but sometimes it just feels that way. My Asperger’s Syndrome makes my brain work differently to people with neurotypical brains. Once I get into a box it takes over all of my thinking and I can only think of that. Each box holds a part of my life. Each is a jail that I find almost impossible to get out of. Sometimes I find I am too scared to get out of my jail and socialize with people. I may be single all my life because I don’t know how to socialize well enough to find a girl who will want to have a loving relationship with me.

In one box I remember the GWN logos. In 1986, it had an oval shape with “GWN” in it and a ring and a dot. The dot represented a satellite and the ring was its orbit. At that time the northern part of Western Australia could not get GWN at a certain time. The program had to be sent to the satellite and beamed back to the north of Western Australia.

In 1992 they removed the orbit and the Satellite from the Logo because they put a new transmitter up which gave the northern part of Western Australia all the time without bouncing off a satellite. They used this oval shaped logo until December 31, 1994. On the first of January 1, 1995 they changed to a new logo which had an object ring around the “GWN” letters. They used this logo until August 31, 2001. On the September 1, 2001 they changed it again to “7on GWN”. In 2002 they removed the “7” from the logo and now the “7” scrolls the “GWN”. After that the “7” disappeared.

You could bump into Lyle anywhere in town and he is always there with a clear purpose. Today he is visiting the Radiology Department of the hospital, trying to get to the bottom of a story about a university research program being on offer right here in our town. It is about a trial of a remedial therapy that had been developed in partnership between a hospital and a university in Melbourne; and has reportedly had some successes with changing functioning for people with Asperger’s syndrome, and others with non-neurotypical brains. The wide smile Lyle has been beaming slightly falters as he receives the words of the receptionist. She is doubtful whether it is available in Albany; Lyle has to work hard to integrate this information with what he holds in his head.

Lyle is taking actions towards one of the most important goals in his plan; that of changing the way his brain works. His dream is to be more ‘neurotypical’. (Lyle adopted this word after hearing Wendy Lawson use it.) Lyle sometimes has difficulty understanding what others are feeling or thinking, and so is unaware that the people who support him are in awe of his formidable mind power. One of the most important things that Lyle tells us about himself is that he does not like being different and would like to be neurotypical. He doesn’t use the word normal he says, because there is no such thing.
Ella: The Right to Change

“When I was living in Albany my house was very cold and I lived behind a school that was very noisy. I wanted a fresh start somewhere else and went to speak with V at CLA and said I would like to move to Denmark. I now have a brand new 3 bedroom house in Denmark and I think it is very good. At first in Denmark I was very lonely and didn't know anyone. I joined the library and got a new library card. I go there every Monday with J and get new books and I go to Robyn and Emily. I go to J's house sometimes and have met J's son, daughter-in-law and grand kids. I like talking to them. I now go to the Denmark Day Centre every Tuesday and have met lots of ladies who go there. We do games and talks and sometimes we go on bus trips. Now I know lots of people in Denmark and I am very happy.”

Ella.
Mary’s story is a good one for portraying the need for a clear aim and a sustained effort towards it. This is an aspiration important to Mary’s family, reflecting their needs and values. Mary is a fun-loving, outgoing woman with a good sense of humour. She is very friendly and loves babies. Someone who doesn’t know Mary well might find it hard to understand what Mary needs or how she feels about things. Mary communicates with sounds and signs. She uses just a few words and so every decision and action unfolds through a process of attuning and interpretation... even this little story.

Getting it right has involved a long process for Mary, for her family and for the people at the CLA. That a supportive family-like environment be found or created for Mary had always been important to her family members. Her family wanted a support arrangement that could accommodate her needs and high level of dependency, but also enable her as much independence as possible and provide her with most of the normal patterns of life.

Mary has journeyed through a number of different homes and support arrangements over a considerable period of time. In 1991 Mary moved from Perth to Albany. She moved into a house with another person supported by the CLA. These two people were the very first supported by the CLA, and so their lives and the challenges of meeting their needs have driven and shaped the organisation from the beginning. After twelve months it became clear that although it seemed like a great idea at the time, in the end it didn’t really work for either of them. It was then arranged for Mary to have another co-resident. Her former housemate also moved out into a co-resident arrangement with a local family and has remained in that family to this day, in contrast, Mary has since had 7 different co-residents.

In 2009, Mary moved in with a woman in a smaller rural community, and hopefully this will be her final co-resident support worker. Mary is finally living the life she dreamt of.

Her co-residency provides the homely environment Mary needed, offering her stability at last. Mary gets involved in lots of different activities during the day. She collects the mail, goes to the swimming pool, collects fire wood and malley roots, loads up the trailer, and helps out with all the daily chores that need to be done in and around the house. This way she keeps very busy. As an animal lover she has a bird and dog to care for. She loves watching footy with her co-resident’s father, whom she adopted as her grandfather. In the small community Mary can safely go to the shops on her own to purchase milk and other small items, giving her a sense of independence. Although Mary enjoys her own personal time, when she enjoys doing things like jigsaw puzzles, she has also been described as a social butterfly.
CLA currently supports 46 people to successfully live in their own homes in the community. This group is widely diverse in age, type of disability, the levels that they need support, the degree to which parents, family members or friends are involved in their lives, and in the style of home they have. Most relevant to implementing Person Centred Planning though, is the degree to which they themselves have been participating in making decisions about their own lives.

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<th>CLA STATISTICS</th>
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<td><strong>69</strong></td>
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<td>People with individualised funding</td>
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<td>People have accommodation support funding</td>
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<td><strong>30</strong></td>
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<td>Females</td>
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<td>Males</td>
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<td>Aboriginal people</td>
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<td>People have a formal guardian</td>
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<tr>
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<tr>
<td>People have no family or family contact</td>
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<td>People live in Albany</td>
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<td><strong>10</strong></td>
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<td>People relocated from another service or region</td>
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What is CLA’s Model or View?
Values and Principles

We have depicted the centre of our model as ‘Values and Attitudes’, representing the foundational and guiding principles of the organisation. Person centeredness and self direction are key values promoted by CLA. Values and attitudes permeate all the layers and elements of the organisation and have a significant impact on the lives of people supported. Unlike more traditional models, the person is not placed diagrammatically at the centre, but rather on the outer reflecting the impact on the person of values and attitudes, planning, practices, management and relationships within the organisation. CLA believe this model is person centred in that it is concerned with the individual outcomes for each person and focuses on the importance of the individual reciprocal relationship between the person and the organisation.

The simplicity of the dolls does not imply a lack of awareness about the complexities of influences on the lives of people with disability. Within organisations there may be additional layers and sub layers. We are aware that influences on provision of services for people with disability extend way beyond the limits of the organisations involved, encompassing the disability sector as a whole and also beyond that to the wider mainstream political and social realms.

Planning, Practices and Management

Some writers have referred to PCP and self directed services as an activity or an element of co-production, though to date, none has offered sustainable suggestions for carrying the information and knowledge beyond the confines of the organisations. Co-production is about working with people rather than ‘doing to’ or ‘providing for’. This is more likely to be achieved when human service workers at all levels are willing to facilitate rather than control and are focused on the outcome for the person rather than the process of service delivery. A probable cause of this is that there are few if any organisations that have effective, sustainable and all-inclusive methods for the people being supported to influence all levels within the organisation itself. Organisations that have begun to implement PCP and self directed services are perhaps beginning to set up the flow of influence to work from the person outward, but as yet there are few reports of how they are going with permeating these into wider systems and processes.

This use of the dolls is a mechanism to morph the theory and concept of person centeredness and self direction into a process, which begins to have some definition and structure applicable in disability service organisations. As well as bringing attention to the depth and some of the detail of the challenges, it displays the potential for people to maximise ownership of their lives. Further, it allows for their engagement and contribution to the systems within the organisation.
Examples of this at CLA include a review by the Buddy Bunch group of how well CLA meets the Disability Service Standards, which fed directly into the annual self assessment. The group conducted this review over three weeks and a written report was provided for Coordinators, Managers and the Board. For CLA the inclusion of people with disabilities and their families in the development of policy is one way in which the organisation can move closer to the goal of greater self direction, a shift in the balance of power and improved life outcomes.

The feedback from Buddy Bunch resulted in changes at the management, planning and practice levels, for example changing the complaints process. Participants did not understand or particularly value the process of reporting complaints to a person in a senior role, rather they felt better supported if they could talk to some-one of their choice who would support or advocate for them.

Some people indicated they were receiving more support than they required, whilst others suggested additional supports would be beneficial. However, a common theme was that the person wanted control over who provided the support. Frustration was expressed at the high turnover of people who provided support. People acknowledged they were generally encouraged to attend and participate in planning meetings, however, several people reported that their contribution was not particularly sought or appreciated. This feedback led to the employment of a Project Officer to assist the CLA improve the way services were offered and provide people with more personalised supports.

Just as this use of the Matryoshka Principle is a means by which to appreciate the scope and the potential of the work of implementing person centredness in service organisations, it may also help in understanding how much ground an organisation might have covered and/or assist in identifying a place to start. All of the work at CLA discussed to this point can be seen to be mostly about the middle layers of our person centred doll, namely planning, practices and management. The next part of our discussion comments briefly on projects and actions that stand as examples of strategies for change at other levels.

The “This is who I am” project presented in the preceding chapter is an example of change in practice, representing the middle layers of our doll. It seems to lead naturally to planning and working with people to extend and apply what they have learnt, then communicated about themselves by creating agreed upon sets of goals and intentions to guide the process of improving each person’s quality of life.

Previous work around creating a culture of continuous improvement had shown up some not uncommon but major barriers, which we again encountered as we began working with people and families to actually formalise planning. Chief among these, are the discrepancies between the everyday practices of staff involved in service provision, the underlying aims and values of the organisation and those of PCP.

Discrepancies of this nature may very well lead to the tenuous relationship between planning and outcomes that has been reported as another of the failures of PCP in some instances. Processes to re-invigorate and communicate the foundational values of the organisation within the organisation have the potential to narrow this particular gap, and in that way affect changes for all the people supported.
The CLA has received many commendations from independent Standards Monitoring visitors over the past eight years, with the majority of these relating to the strong values base and the positive life outcomes for the people supported. The stories people have shared earlier are certainly the best testament to the positive values of the organisation and the commitment of the direct support workers involved. Obviously there is and always will be a need for aligning individual values and attitudes to the values and mission of the organisation. One of the ongoing challenges of working with a continually and rapidly turning group of staff is that of ensuring that the right person is doing the right thing in the right way, and at the right time.

The organisation also continues to need to respond to a never ceasing set of internal and external challenges and pressures, growing and evolving as it does. Complex adaptive systems theory as it relates to organisational development provides a model for understanding how growth pushes organisations through various different phases and stages, some of which border on chaos. In fact chaos, in which elements are relatively disconnected from each other or in challenging relationships, is said to be as essential to creativity and innovation in any field, as it is unnerving for organisational managers.

Though SRV as a concept and practice began in 1972 it has continued an unbroken history of application similar to model coherency. Model Coherency and PCP concepts and challenges have since been particularly evident in more stressful times and situations, and consequently will have a significant impact on their day to day practices. This is continually challenging their own negative and unhelpful assumptions, these well founded and articulated values and principles, if workers do not understand and articulate outside of a group of devotees. There are a significant number of other sources and more informed writers addressing SRV and discussing its history and developments to date, including ‘Model Coherency’.

In a nutshell, ‘Model Coherency’ is an important concept in SRV and is a measure of how well the component parts of a service fit together. It is a way of measuring if the service actions are what they say they do, if all the written and stated values and attitudes match the actions of how services are provided. Contemporary Model Coherency workshops for the disability sector are structured as a means of challenging and educating people about their own assumptions, as well as providing processes whereby people can evaluate the organisation’s and their own application of the principles of SRV.

Staff at CLA, including support workers, service coordinators, administrators and management participated in a series of model coherency workshops. In the workshop the theory of model coherency is explored and the understandings and principles applied in consideration of the experience for the people supported by the organisation. In spite of an organisation having well founded and articulated values and principles, if workers do not continually challenge their own negative and unhelpful assumptions, these will have a significant impact on their day to day practices. This is particularly evident in more stressful times and situations, and consequently on the quality of life of the people they support.

Model Coherency and PCP concepts and challenges have since been introduced into CLA staff orientation and induction, and review and supervision processes. Sustaining and supporting staff to continue to challenge both their own unhelpful assumptions and those underlying the habits and culture of practice, and if necessary, change the way they work, is part of the role of the service coordinators. However, developing a culture of reflective practice by all staff at all levels of the organisation where people are comfortable to challenge policies, procedures, systems and individual actions supports the relationship between values and attitudes and the other layers in the model. Effectiveness in this role goes a long way towards ensuring that the right values and attitudes are operating in daily practice, a layer represented in the middle of the doll right alongside that of the ‘planning’ layer.

Coordinators are very influential in these middle layers at the CLA and ongoing learning and growth has been the focus for other strategies to improve our ability to facilitate quality outcomes for people. For example, we participated in a national workforce enhancement project that focused on job redesign, organisational change and improvements in our recruitment and retention strategies. Our goal was to ensure continuity of support for people by retaining a skilled workforce with the right values. Historically the middle management level in human service organisations has been overlooked and under supported, which can lead to people having great intentions but a lack of clarity or guidance from the service in how to facilitate good planning and outcomes for people.

Over time many CLA coordinators have expressed frustration about the challenges and their role in managing them. The trials of shaping teams into faithful representatives of the ideals and values of the organisation and finding the time and resources to engage with people in person centred planning activities remains the most important but equally challenging part of the role. Following participation in the model coherency workshops the service coordinators gained a new focus since, admittedly in initial feedback, reflecting both belief and experience, that although they appreciated that the knowledge could be applied to improve the quality of life of the people supported, when back at work, the immediate demands of the role swamped their attention. A similar thing had happened following introduction and mentoring to implement PCP with external influences contributing to this sense of frustration for Coordinators. These included a high turnover of staff, low unemployment which led to fewer people applying for support work and the organisation experiencing growth in the number of people being referred, particularly people with high support needs and or behaving that was challenging.

Through our involvement with the national workforce development project hosted by National Disability Services, Queensland new workforce positions were created which eased some of the stress on the Coordinators. The new positions took away some of the administrative tasks allowing them more ongoing learning and growth has been the focus for other strategies to improve our ability to facilitate quality outcomes for people. For example, we participated in a national workforce enhancement project that focused on job redesign, organisational change and improvements in our recruitment and retention strategies. Our goal was to ensure continuity of support for people by retaining a skilled workforce with the right values. Historically the middle management level in human service organisations has been overlooked and under supported, which can lead to people having great intentions but a lack of clarity or guidance from the service in how to facilitate good planning and outcomes for people.

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Through our involvement with the national workforce development project hosted by National Disability Services, Queensland new positions were created which eased some of the stress on the Coordinators. The new positions took away some of the administrative tasks allowing them more chance of supervision and support for staff and individuals receiving service.

Following the model coherency workshop the Coordinators and PCP Project Officer held a series of fortnightly facilitated meetings to learn and apply skills in critical reflection on the application of the principles of SRV and PCP. This enabled them to initiate change in how they thought about, arranged and or facilitated support for people. This is an example of a strategy to stimulate and sustain change in one of the middle layers of the doll and transfer the central values to the other layers. In our situation the facilitated meetings strengthen the transfer of values and attitudes from the centre outwards to the planning and practice layer and on to the management layer.

Coordinators were helped to develop a list of statements reflecting the values and principles of SRV as they relate to all the domains of support. The Association became involved with the Personalised Residential Supports (PRS) project which identified key themes that are present in personalised supports.
Building upon this, the Coordinators and Project Officer developed a checklist that linked indicators of personalised supports to the new outcome reporting framework as a tool for evaluating the support that people were receiving. The checklist was developed to cover all program areas of support, not just for those in receipt of accommodation funding.

Coordinators were then individually supported to consider the statements that reflect the values and principles of SRV and PCP as developed by the Personalised Residential Supports project headed by Prof Errol Cock and Ross Boaden from Curtin University as an aid in developing reflective practicing skills. These include skills such as observation, questioning, thinking aloud, and noting where existing knowledge is enhanced through new ideas. They began with a case study and used the checklist to identify where support arrangements for that person did or did not uphold the principles, marking true, false or uncertain against each statement. They were then encouraged to note any items which were problematic, posing ethical dilemmas or any other circumstances which precluded a straightforward answer.

In the next series of sessions each coordinator presented their case study in turn. The outcomes of the individual evaluations were then discussed in the group, and all participants were invited to challenge and question the presenting coordinator’s validation of the assessments given. Participants were supported to comment on any realisations that they felt had a strong impact on their own previously unconscious assumptions, and to identify and consider where and why it might not be possible to ever achieve the standard set by the list. Participants were also invited to provide feedback to each other and to the facilitators about the group process as it was unfolding.

Participating in the program led to change in the support arrangements for several people. A number of coordinators reported having more confidence in being able to support their staff in recognising and correcting unhelpful patterns of interaction with the people. One example of change comes from a situation in which it was very difficult to interest two people with a disability who shared a home to participate in ownership duties. Through use of the observation and questioning tools of reflective practice it was discovered that although there was no overt conflict between them, they were just not interested in each other and if given a choice would not have been sharing a home.

Though this sounds simple enough, this insight represents a major breakthrough in reflecting on a long standing problem, as well as a major challenge in delivering support services to the two people in question. The lack of overt conflict meant that without review these two people may have remained sharing a home and maintaining the status quo, missing out on opportunities to form relationships with people they actually liked and enjoyed the company of. It also serves to prompt people to think about what else might have been overlooked concerning these people and others before them. Revitalising expression of the principles of SRV serves to demonstrate the potential to force a change in systems and practices which affect all people being supported. This is because the attitudes and unconscious motivations of all people involved in the provision of services are considered to be part and parcel of the ‘system’. It certainly has the potential to enhance the effectiveness of PCP, as this is one of the underlying principles of SRV.

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**Planning Practices and Management**

**Values and Attitudes**
- The values, attitudes and assumptions that define relationships, planning, service delivery, control, self direction.

**Planning**
- Occurs at or before the referral stage and is ongoing.
- Planning may be formal and / or informal

**Practices**
- “What we do here’ and ‘how we do things here’ defines the culture as determined by values and attitudes . Must be responsive to planning and self direction

**Management**
- Refers to governance and the systems that influence how services are delivered including power sharing, control, flexibility and responsiveness.

**Relationships**
- Refers to the commitment to develop and maintain relationships within the service, between people, systems and external stakeholders.

**Person**
- The quality of life for the person is directly impacted by the other layers.
PCP is considered to be one of the best practices for ensuring continuous improvement of quality of life. However, not everyone with a disability needs or wants this for themselves. Many people do not ‘plan’ their own lives. The skills of strategising, planning and preparing for distinct steps of action can obviously be learned, but not everyone sees the need or wants this.

If planning comes across as an unnatural practice for many, how much more so collective or group planning will, not to mention formalised, documented and reviewed collective planning. Agreeing on priorities, goals and strategies and then adhering to what has been decided, and getting comfortable with some level of obligation and responsibility to the collective voice, requires a considerable change in thinking, communicating and doing.

In working with people with disability a primary task is to find an approach that can be mastered, or at least made meaningful by and for the people supported and the people who will provide the support, both to meet the goals and foster empowerment of the person. We know that such change is a process, not an event, and starting with small, relevant and achievable goals and shifts in ownership is a key to both success and sustainability.

It proved important that we at CLA started where we were all at collectively. The challenge was to find a suitable model. We needed it to be encompassing enough in its focus to incorporate and respond to the needs into which we were putting a lot of effort and focus; flexible and able to be accessed by all who would want to develop a person centred plan, regardless of the level of support needed. Also, given all the constraints, including but not limited to those to do with staffing, accessibility and funds for training; it needed to be relatively easy to grasp, recorded in user friendly format, able to be adjusted as required, kept track of, and to able to compile reports from.
The Life Quilting Style is very similar to Essential Life Planning which had been used previously by CLA. It was developed and formatted so that people could record information as a series of patchwork sheets. We discovered it in a book by Don Kincaid on positive behaviour support for people with difficult behaviours. The ‘Quilting’ is nicely evocative of the creative task of exploring and bringing different elements to a person’s life. From the ‘snapshot’ that then emerges, gaps and needs can be easily identified, new directions forged, and new opportunities created.

Focussed as it is on involving everyone: the person, their family and close others including direct support workers; and considering the whole spectrum of life, this style appeared to have the optimum potential to be accessible for most people. It seemed and proved to be an ideal way to have what people were learning about themselves in group settings formally considered, and applied for immediate impact and change in many other aspects of their lives. People who were only minimally able to communicate about themselves before could be authentically and meaningfully engaged in some of the processes. Importantly too, the views, hopes and concerns of significant people in their lives could be easily considered and incorporated.

The framework of Life Quilting can be inclusive of all the essentials of positive behavioral support. As has been established, it has been an excellent facilitator for other initiatives, such as the Personalized Information Project. From an administrative point of view, this project seemed to offer an improved way to record changes and improvements which would go a long way in assisting the organisation to meet the new outcome reporting requirements that were emerging in the disability sector. We anticipated that life quilting would be flexible in terms of focussing on each individual’s unique situation and subsequent needs.

The way Don Kincaid has written about the application of Life Quilting also encouraged us to just get down to business and start implementing it without waiting for formalised training or specialised resources. PCP’s were developed with 8 people and their families, guardians and advocates. The processes of developing the plan was lengthy and there were varying levels of commitment and support from the person themselves and others involved. For one person the commitment to reviewing and updating the plan continued for 4 years, however for others the systems within the service for review and the complexity of the plan meant that this method of planning and documenting goals was not sustainable. Further, the number of people that had person centred plans developed remained low.

The increased knowledge on PCP didn’t flow easily into documented plans for many people even with changes at the management, planning, practices, relationships and individual support levels of the organisation. This did not occur until we introduced a simpler but equally effective process for documenting people’s goals and vision for their own life based upon outcomes. We revisited the SRV, PCP checklist that was developed. Coordinators met with the person, their family, support workers and where appropriate advocates and friends to develop a plan that identified people’s vision of their own life. Once this had been identified and documented, the individual strategies to support people could be linked to the principles of personalised supports and the various outcomes that CLA must report on. This new approach resulted in every person supported by CLA who wanted a documented plan having one developed.

The simpler template for documenting people’s person centred plans was influenced by a number of other factors. Moving to a new outcome reporting framework meant that the CLA needed to have a clear process for gathering the relevant information for reporting purposes. Becoming focused on outcomes and less on the process of developing the plan was the shift in thinking required and this also occurred at a time that the service was committed to greater self direction for people. This influence was largely external and represented a shift back to ways of working with people when the organisation was much smaller and less formalized. This would not have been possible without the concentrated efforts to understand the interface between people, relationships, policy, management, planning and values and attitudes of the individuals with in and the organisation itself.

Staff of CLA would be described as person – centred; many people are chosen for work because they demonstrate this, if being more important in the selection process than either previous experience or qualifications. Person-centred thinking is obviously an essential quality for effective PCP, but it does not guarantee effectiveness. Being person – centred may come naturally for staff, planning, however, may not. Many people do not plan their own lives. The skills of strategising, planning and preparing for distinct steps of action are relatively easy to learn, though not everyone sees the need for it or is available for the learning.

The nature of the evolution of approaches in the disability sector, especially in services, seems chaotic and somewhat competitive, much like in any other political arena. There are mechanisms and forces at play that result in the newest bright idea becoming the flavour of the month and rendering all previous development somehow old hat, even if and when the new is not much more than a disguised version of what went before. This is not the focus of this publication. For that reason it is timely to propose a person centred approach that fits with current thinking around greater control and self direction for people who are in receipt of formalised services.

People involved in the work at the CLA did not initially set out to create a model, however, as we merged what we were learning through our own earlier innovative practices in supporting people to learn about and voice themselves, we realised that we were actualising the spirit of person centred practices and self direction in ways that make planning more meaningful for the people we support. We can only hope that our collective efforts and commitment to continued learning will result in achieving our vision of greater self direction for the people the CLA serves.
Bibliography


