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# Exploring and Implementing Person Centred Approaches

A Guide for NSW Community Participation Program Service Providers

NSW Department of Ageing, Disability and Home Care



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*'Exploring and Implementing Person Centred Approaches'* is the work of a consortium comprising Australian Catholic University (ACU), Ellis MacRae & Associates and Sherwin & Associates. ACU, Faculty of Education, provided research and administrative support to the team of people who were commissioned to develop the guide. The team members are:

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Jane Sherwin who has been involved in the lives of people with disability since the late 1970s in a range of service roles and as an academic. She works with groups and organisations on values based quality, person centred approaches and leadership development. Jane has a strong reputation in working with service providers who are interested in developing responsive services and supports.

Trudy van Dam who is an academic working in the area of inclusive education and disability studies at the Australian Catholic University. Trudy has had 20 years experience in service provision with 10 years as the CEO of a large service provider. She was responsible for implementing sustainable person centred approaches which brought significant change to the lives of people with disability.

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## Foreword

Person centred planning forms a vital framework for the delivery of services both now and in the future, establishing a partnership between people with a disability, their families and carers and the organisations which support them.

This emphasis on a person centred approach is reflected in the DADHC funded Community Participation Program and its Guidelines, through which services support young people with a disability to achieve their goals and increase their independence and participation as valued, active members of the community.

Person centred planning is not a new approach. Its practice, however, challenges us to consider the ways it can be implemented both on a practical everyday level of service delivery and also more broadly embedded in all aspects of an organisation's management and objectives.

This guide has been developed in recognition of the central importance of person centred planning especially at the transition stage in a young person's life when moving from school into other pathways. Person centred planning gives an opportunity for exploration and encouragement of a young person's dreams and goals and provides a vehicle for those aspirations to be achieved.

I am very pleased to present this guide and would encourage all service providers to explore the 'terrain' of person centred planning and its implementation.

### **Lauren Murray**

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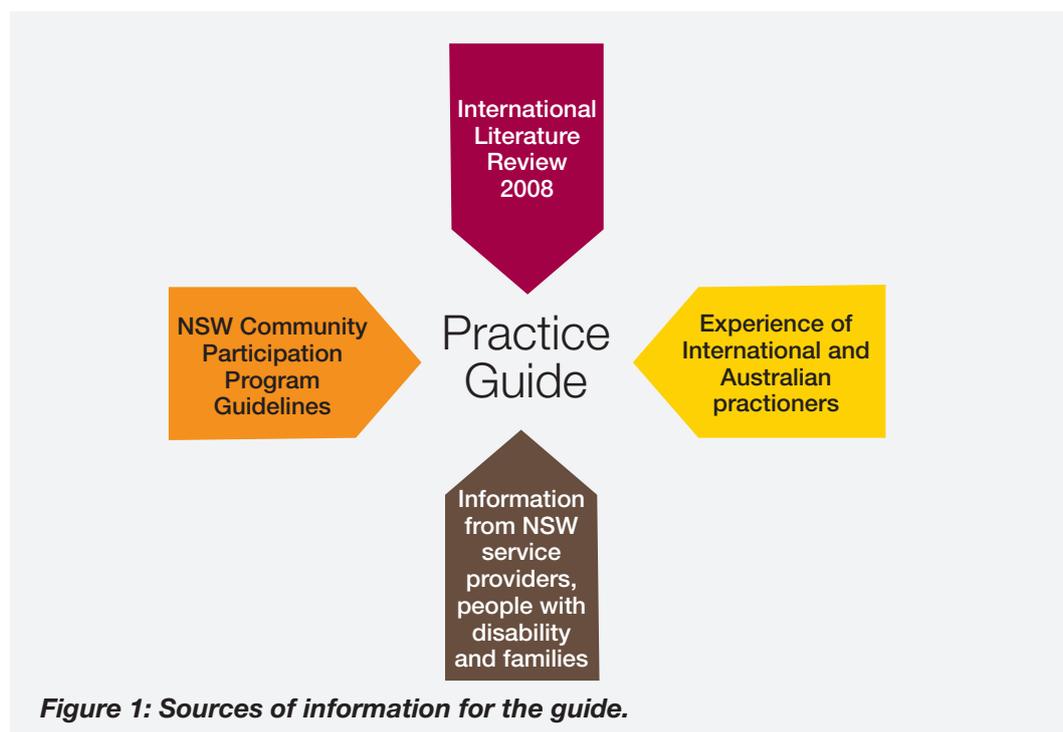
## Introduction

This resource is primarily a guide for NSW Community Participation Program disability service providers involved in the range of community participation service types. It has also been written to assist people with disability, families and advocates understand the positive differences that can occur in their lives when an organisation is committed to person centred approaches and thinking. This resource may also assist school leavers, and their families, to obtain information so that they can make informed decisions about their futures.

The content of the guide is drawn from information gained from:

- a comprehensive review of published research and other literature about person centred approaches
- case study interviews with people with disability, families, senior managers in disability service providers and community organisations from across NSW
- the experience of international and Australian service providers, academics, professionals, educators, commentators, change agents and policy makers
- the NSW Community Participation Program Guidelines 2006

as shown in Figure 1 below.





The guide therefore starts from a place where a significant amount of learning, thinking, action and change has already taken place and brings this together to assist NSW service providers, people with disability and families.

The guide is not a manual. It does not give step-by-step instructions. Rather it is intended to:

- assist service providers understand the broad 'terrain' of person centredness
- explore and understand the significant implications for their organisations, systems and structures
- bring service providers to an understanding of what it will take to make the move to person centred approaches and thinking
- focus on practices which are essential in order to meet the Principles and Key Result Areas of the NSW Community Participation Program, and which will support the move towards person centred planning in the program
- inform service providers of strategies and practices which are fundamental if person centred planning is going to make a difference in the lives of people with disability
- provide people with disability and families with information about how person centred approaches can positively affect their lives.



## What is planning?

Planning is something that everyone does around big and small decisions in their lives. Often it is triggered by change such as leaving school and having to think about the future, planning to move house or to get a new job.

Using the example of leaving school and having to think about the future, a young person would start with their own individual and unique interests, what they are good at, what they enjoy doing, what roles they would like to take up, how they would like to earn money. The young person might also look to what their peers are thinking of doing and emulate them. Many will often be guided by their family or will seek advice from someone known to the family. They may follow their older brother or sister into tertiary education or part-time work. They may look to a place in a family business. Family and friends will provide contacts they know who might offer a start. Family members will often help with writing job applications, lend the person some money or assist the person travel. All of these ideas are part of a plan - a person centred approach - which, if acted on, assists the person achieve their goals and aspirations.

This significant, but typical, episode in most people's lives provides some essential principles. These are:

- it is the person who 'owns' the planning. It is their interests, identity, culture and aspirations which will guide what they want to achieve in life
- others are asked for advice and ideas and typically these will be people who know the person well
- professionals may be contacted to seek advice
- the person and those who know them well will decide what advice is taken and acted on
- the person will decide what is important to them, not only what is important for them
- they will decide on the priorities and the compromises that may have to be made to put the plan into action
- the person will have much to say about how things are going and will seek further advice or make changes if things don't turn out how they were expected to
- the plan is not the goal – the plan is how the person is going to achieve the goals they have set for themselves
- goals will change over time.



## Planning in the lives of people with disability

Evidence and experience show that the principles outlined above have generally not been the ones which have guided the lives of young people and adults who have a significant disability. For most people, their future is not based on the individual interests, identity, cultural heritage or aspirations of the person or the knowledge and experience of their family and friends. Rather it is overwhelmed by the effect of the disability, stereotypes, low expectations about achieving ordinary dreams and aspirations and by a human service system which is influenced by history.

When young people with disability are leaving school and striking out into the world, a time where good planning is most required, the future lives of many young people with significant levels of disability are often shaped very differently to that of their peers who do not have a disability. In the main, they and their parents are expected to choose a disability service provider and generally, they are fitted into activities and programs which have been designed by others who do not know them.

This is perhaps the most important reason why it is vital that individuals and their families are given opportunities to develop their own picture of a desirable future and take some control of their destiny.

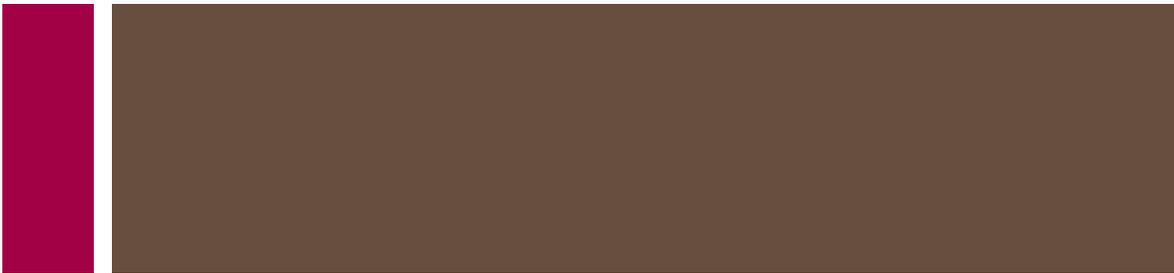


***“Everyone has the right to dreams and opportunities.”***

***(NSW Community Participation service provider)***

Person centred planning puts the person with disability at the centre of the planning, listens deeply to them and their family and friends, learns over time what it is they want for their life now and in the future, and then acts on this.

**It means a shift of power.**



## What is person centred planning?

Person centred planning has been used for over 20 years and, in that time, there has been much learning.

It cannot be explained with a simple one-sentence definition. In fact, the use of the word 'planning' leads to significant misunderstandings and a focus on doing a 'plan', rather than the more important essential components of listening and thinking with the person, learning what it is the person and their family want, and responding to providing the supports needed to achieve the goals and aspirations of the person and their family and friends. The process is embedded in the person's social and cultural context and therefore reflective of, and responsive to, their personal, social and cultural circumstances. Probably the best way to ensure that its complexity is understood is to quote from some of the people who have written about, practised and taught person centred planning over the years.

Helen Sanderson describes it as:

*"...a process of continual listening and learning, focused 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 to replace individual program 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."*<sup>1</sup>

A definition of person centred approaches concludes that they are:

*"...ways of commissioning, providing and organising services rooted in listening to what people want, to help them live in their communities as they choose. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. Person centred approaches look to mainstream services and community resources for assistance and do not limit themselves to what is available within specialist services."*<sup>2</sup>

1 Sanderson, H. (2000) PCP: Key Features and Approaches, <http://www.helensandersonassociates.co.uk>  
2 Valuing People – A New Strategy for Learning Disability for the 21st Century. Guidance for Implementation Groups, <http://valuingpeople.gov.uk>



The NSW Community Participation Program Guidelines state that service providers should move to person centred planning and identified five key issues. These are that:

- the person is at the centre
- their wider social network is involved as full partners
- there is a partnership between the person, their family and the service provider
- the whole of life is considered
- there is continued listening, learning and action.

All services are expected to be delivered in accordance with the Principles contained in the Guidelines, the first of which is:



***“...person centred – that people and their families/advocates should be the drivers of their own plans, having control over important decisions that affect their lives...”<sup>3</sup>***

Several principles are drawn from these various definitions, descriptions and guidelines:

- a focus on the person and who they are
- future orientation – concentrating on the aspirations and hopes and dreams the person and their family have for their future life
- the active involvement of family and friends
- a shift in power and who holds power and control
- a clear value base of achieving genuine social inclusion and community participation
- a signal for the leadership and staff of service providers that there have to be fundamental changes to how they interact with people with disability and families and how their organisation looks and acts.

*“...through the application of these principles, person centred approaches provide a sensitive way of understanding and responding to a person’s needs. It has been noted to be an important way of providing culturally appropriate solutions because it is based on the unique priorities and perceptions of the person, their family and their cultural context...”<sup>4</sup>*

<sup>3</sup> NSW Community Participation Program Guidelines 2006, DADHC, [www.dadhc.gov.nsw.au](http://www.dadhc.gov.nsw.au)

<sup>4</sup> Callicott, K.J. (2003) Culturally Sensitive Collaboration with PCP. *Focus on Autism and Other Developmental Disabilities*, 18(1),60-68

This practice guide concentrates on the cultural and organisational change required and highlights six essential elements which are required so that service providers can place themselves in a position to respond effectively and flexibly. The elements speak to the fact that moving to person centred planning is much more than adopting the language or the tools. They act as the lens through which to appreciate the extent to which a service has embraced person centred approaches. See *Figure 2* below.



**Figure 2:**

***Essential elements of organisational change to bring about person centred approaches and thinking.***

## Organisational change, cultural change and person centredness

*“.....for organisations to move away from systems-driven services to supports that are person centered, shifts in the organisation’s strategic direction need to happen. .... culture, leadership, organisational structure and the design of supports to individuals must align with the values of person centered approaches and thinking.....”<sup>5</sup>*

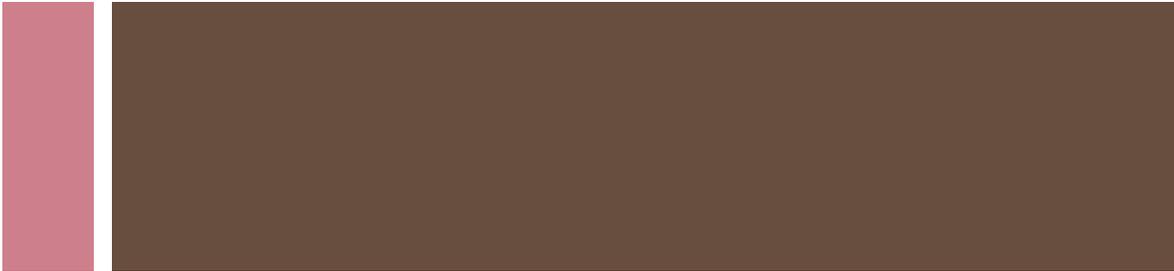
All leaders and senior managers in large and small organisations engage in thinking about organisational change for a variety of reasons. The impetus typically arises from both external or internal forces or environments. An internal force may be that the organisation wants to get better at what it does for the people it has been set up to serve. Leaders in organisations where this is the driver recognise that there are significant benefits, not only for the people the organisation serves, but for the organisation itself and its stakeholders including board/committee members and front line staff.

### Benefits for organisations

Leaders who are thinking through the changes required to become an organisation which is person centred and to create a culture which reflects person centred approaches and thinking recognise that:

- people with disability will live better lives
- staff will have increased motivation, more energy and are more likely to stay
- there will be renewal as people with different skills are attracted to the organisation
- there will be less complaints as people and families realise that they are being listened to and that there is a genuine sense of partnership
- the organisation will be better able to develop culturally appropriate responses to the needs of people from Aboriginal and culturally and linguistically diverse communities
- time and financial resources will be used in a way which focuses on the people the organisation serves
- the community will respond to the organisation in a different light resulting in more opportunities to build social capital.

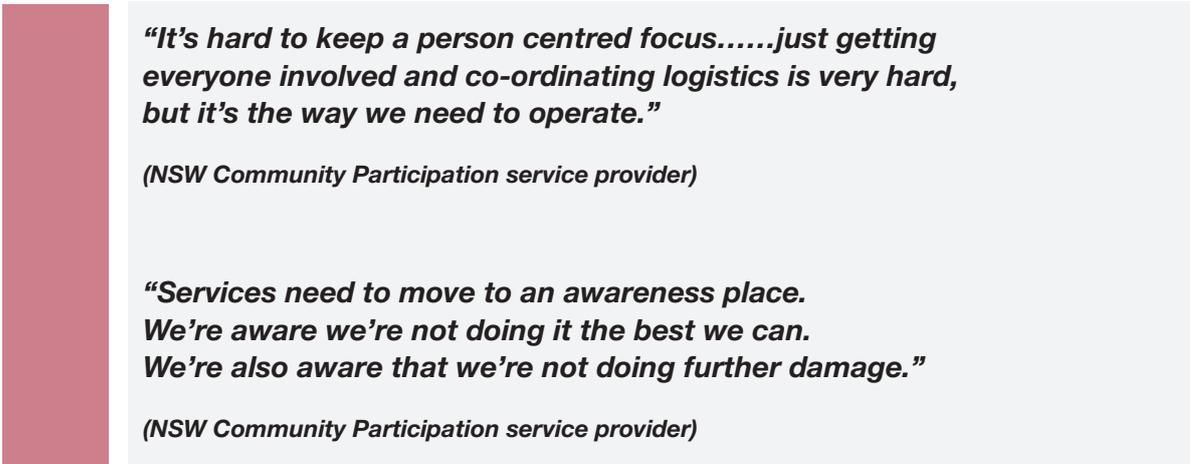
<sup>5</sup> Cornell University, Person Centered Planning Education Site, <http://www.ilr.cornell.edu/edi/pcp/>



In addition, they are motivated by it being the right thing to do! It is ethical in that it is based on positive assumptions about the capacity of people with disability and their families, and on the rightness of them having ordinary lives with a valued status and exercising authority in their own lives.

### **Challenges for organisations**

Change is challenging and complex. There could be anger and denial as some people at all levels of the organisation judge that the change means that their past and current efforts are not considered important. Some people will resist through fear of failure. People with disability and families may be resistant, driven by a lack of experience with alternatives, resulting in a fear of the unknown. They may think it heralds that the organisation is going to reduce their support. It could be interpreted as a threat to what made the organisation 'successful'.



***“It’s hard to keep a person centred focus.....just getting everyone involved and co-ordinating logistics is very hard, but it’s the way we need to operate.”***

***(NSW Community Participation service provider)***

***“Services need to move to an awareness place. We’re aware we’re not doing it the best we can. We’re also aware that we’re not doing further damage.”***

***(NSW Community Participation service provider)***

The challenge and struggle around the differences between being person centred and long-established ways of operating will need to be acknowledged and there will be a need for everyone to be prepared to explore this new terrain together.

*“Person centredness engages powerful emotional and ethical issues – it calls for a sustained search for effective ways to deal with difficult barriers and conflicting demands.”<sup>6</sup>*

A good place to start is with the difference between person centred approaches and with traditional ways in which people have received services.

<sup>6</sup> O'Brien J. & Lovett, H. (1992) Finding a Way Toward Everyday Lives, The Contribution of Person Centered Planning, <http://thechp.syr.edu>

Person centred approaches	Traditional approaches
Focuses on individual's unique interests and preferences	Focuses on individual from a disability professional viewpoint
Builds on strengths and high expectations that everyone can and should enjoy the 'good' life	Commences from a deficit and needs basis and low expectations
Offers beyond what is currently available and works towards the future	Looks to what is currently available from a service
Focuses on organising individualised, natural and creative supports and reduces reliance on the service system	Planning assumes the person will spend most of their time grouped with other people with disability
Situates power and control with the person and their allies	Situates power with the professionals
Tailors supports to achieve the person's goals and future	Fits the person into the service
Aims for social inclusion, valued roles and community participation	Largely limits the person to disability specialist programs and centres

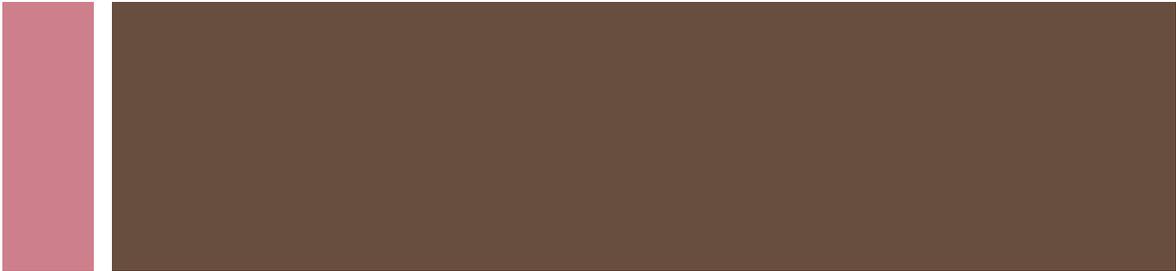
From this it can be seen that person centred approaches are very different to individual program planning with which most individuals with disability, their families and service providers are familiar.

***“In person centred approaches the control is with the person and their family rather than the service.”***

*(NSW Community Participation service provider)*

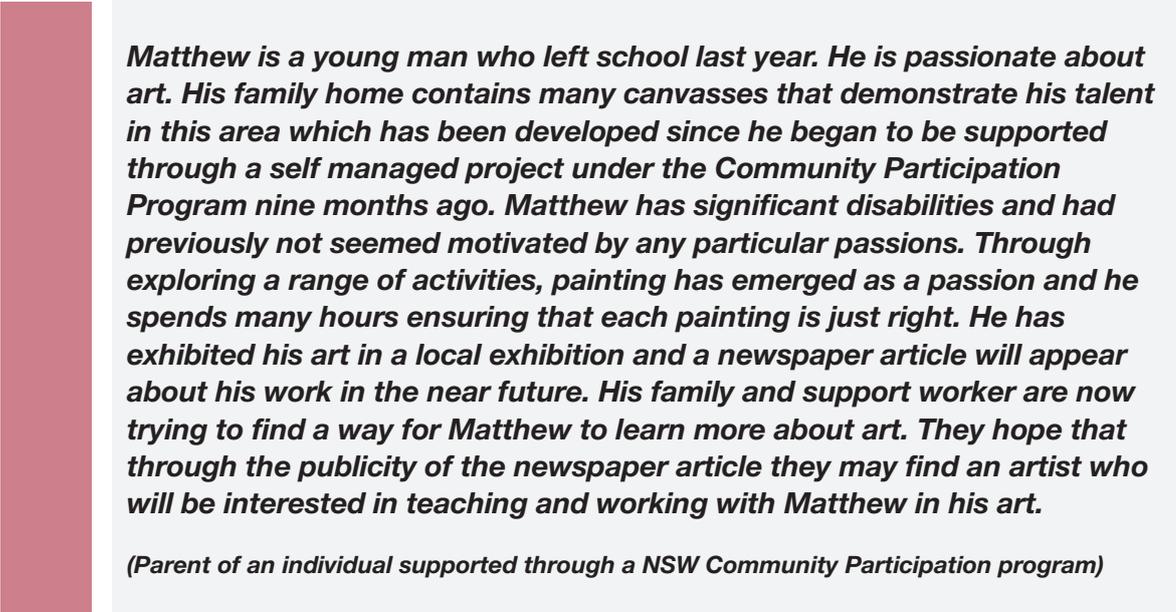
***“My sense of the individual program planning model is that it means well but that it meets the needs of the service, as determined by the funding body.”***

*(NSW Community Participation service provider)*



Person centred planning can achieve very significant change in the lives of people with disability when it is approached and acted upon in a way which reflects its complexity and where there is recognition of the person's broader life. This complexity includes fundamental changes in the way that service providers relate to people with disability and their families.

The disability service provider will become a bridge to the future for the person. They will move to be people who assist the person make new connections and opportunities in the wider community; they will allocate the person's funding differently and they will learn how to bring the support together around the individual, not group the individual with others in programs and activities.



***Matthew is a young man who left school last year. He is passionate about art. His family home contains many canvasses that demonstrate his talent in this area which has been developed since he began to be supported through a self managed project under the Community Participation Program nine months ago. Matthew has significant disabilities and had previously not seemed motivated by any particular passions. Through exploring a range of activities, painting has emerged as a passion and he spends many hours ensuring that each painting is just right. He has exhibited his art in a local exhibition and a newspaper article will appear about his work in the near future. His family and support worker are now trying to find a way for Matthew to learn more about art. They hope that through the publicity of the newspaper article they may find an artist who will be interested in teaching and working with Matthew in his art.***

***(Parent of an individual supported through a NSW Community Participation program)***

The literature and practice reveal that if, as shown in figure 3, different forms of planning are inserted only at the interface between front line workers and people with disability, the outcomes will likely be disappointment, frustration for everyone and little, if any, change in the lives of individuals with disability. This is because the organisation as a whole has not put itself in a position to be able to respond to the plans and goals being developed.

Rather, where there has been intentional culture and structural change throughout the organisation as a whole, the benefits to individuals, their families, the community and the organisation itself will be evident. Organisations will be more effective at carrying out their mission and able to respond at all levels to enable the person to be truly embedded as part of their community. There will be increased motivation in staff, and significant positive changes will occur in the lives of individuals. This is illustrated in figure 4.

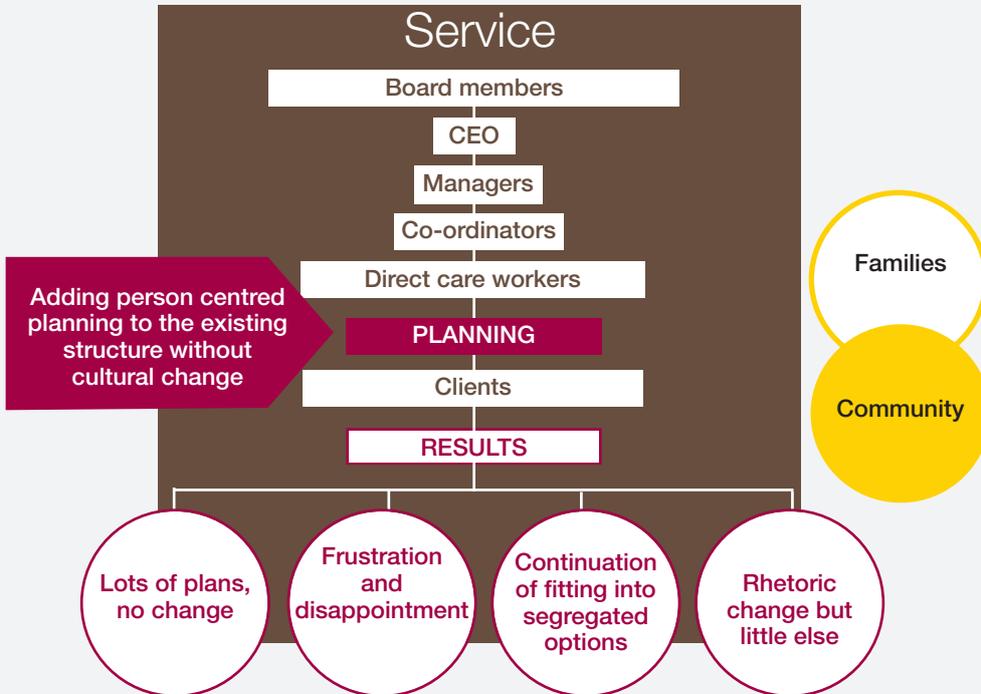


Figure 3: Where person centred approaches and thinking are more likely to falter

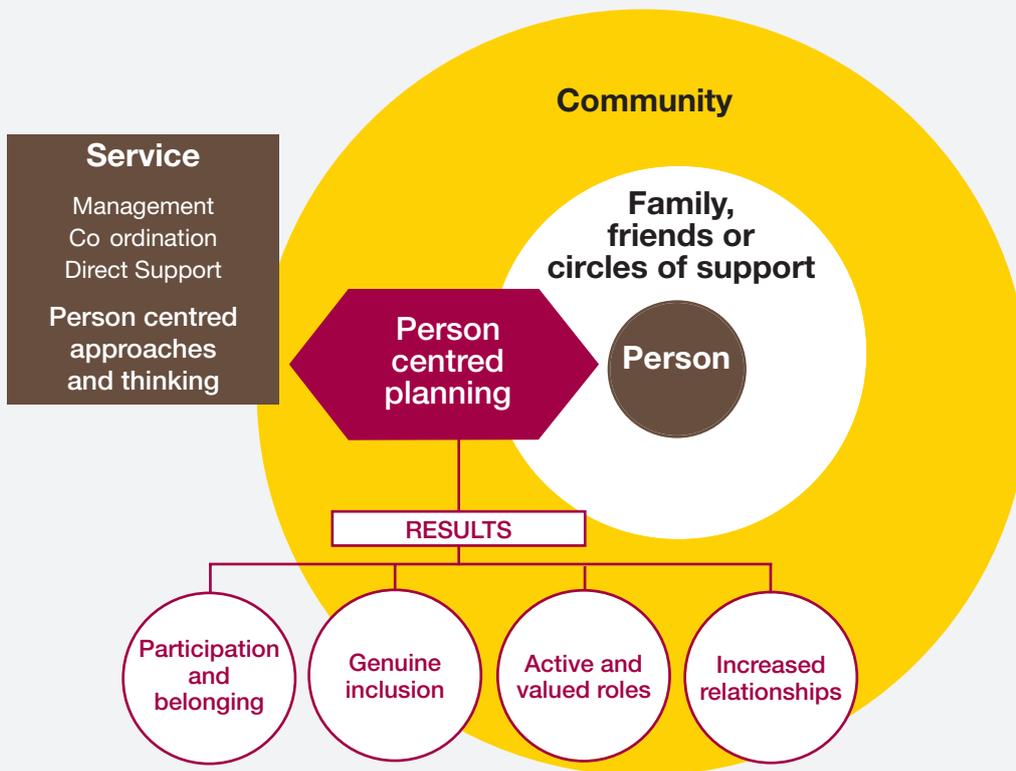


Figure 4: Where person centred approaches and thinking are more likely to flourish



Other leaders in organisations which are enabling personalised and highly individualised support arrangements say that those working in their agencies now:

- embrace flexibility, change and adaptation above predictability and uniformity
- deploy resources (staff and funding) in many different ways rather than resources being used on fairly static types of assistance and programs
- are openly uneasy with expecting people to fit into a fixed set of activities and programs
- have entered into a different relationship and discourse with the community
- focus on the future for each individual
- through partnership with people, their families and friends, share the responsibility and decisions
- experience increased satisfaction in their work.

## Where to start?

Person centred approaches and planning can be likened to ‘disclosing tablets’ which allow the user to reveal what needs to happen but don’t fix the problem. For disability service providers, becoming person centred will reveal what they need to do. Issues to be considered are how the organisation:

- views people with disability
- interacts with families of people with disability
- relates to the broader community
- spends money
- defines staff roles
- exercises authority and power.<sup>7</sup>

While this level of change may seem unattainable to some service providers, there are organisations in NSW which have already started.

***The organisation was supporting people who were registered with the Community Participation Program and also people who attended the block funded day program. The agency spent a long time understanding what was meant by person centred approaches, supported key senior staff to attend training, and engaged in a critical internal review that had the support of the CEO and Board. Their reports were highly critical of what was happening at both staff and service user levels, and in particular that they were not meeting the Community Participation Program Guidelines.***

***“This created the door for easing in person centred approaches ... PC is a good medium for change. This was followed by separating the community participation individuals from the block funded group: We broke the funds up.”***

***The service has been engaged in multi-level strategies of change, targeting the roles and skills of workers, the internal service processes and recording tools. The service is actively making links with like minded others, so that they can provide mentoring and critique. One of the strong beliefs of the agency is to ‘hasten slowly’, ensuring that the philosophy underpinning person centred approaches is embedded in the agency.***

***(NSW Community Participation service provider)***

<sup>7</sup> Adapted from Valuing People – A New Strategy for Learning Disability for the 21st Century. Guidance for Implementation Groups, <http://valuingpeople.gov.uk>

## What will it take?

The findings of a comprehensive literature review, research and NSW case study information show clearly that it will take leadership and action at board and senior management level. It is no use asking direct support workers or case workers to engage differently or do planning with people with disability and families, if the organisation cannot respond or is not prepared to act differently.

Experience in the cultural and structural changes that will be required demonstrates the need for organisations to move to a situation where they:

- are committed to know each person and seek to understand them
- have a conscious resolve to be of genuine service
- be open to be guided by each person and the people who know them well
- demonstrate a willingness to struggle
- display flexibility, creativity and an openness to try what might be possible and if it doesn't work, not to give up
- enhance the humanity and dignity of each person
- look for the good in people and help bring it out.<sup>8</sup>

***“Developing person centred thinking in staff naturally flows to person centred practices.”***

***(NSW Community Participation service provider)***

<sup>8</sup> Adapted from Kendrick, M. (1997) The Leadership Challenge of Service Quality, *Interaction*, 11(1)



The following questions will assist service providers assess their capacity to engage in organisational and cultural change.

*What commitment to adopt person centred approaches exists in the organisation, as expressed by people with disabilities, families, staff and the senior management team?*

*What capacity is there to generate a vision of the future of the organisation and for there to be intentional development starting from what exists and directing the organisation to the future?*

*Are there leaders in the organisation, including people with disability and families, who can form the most effective change group? If not, how will such people be found?*

*How will the service leadership start the process and where would be best to make a start?*

*What communication strategies will be developed for effective communication with all levels of the organisation so as to generate clarity, excitement, urgency, vision and ideas?*

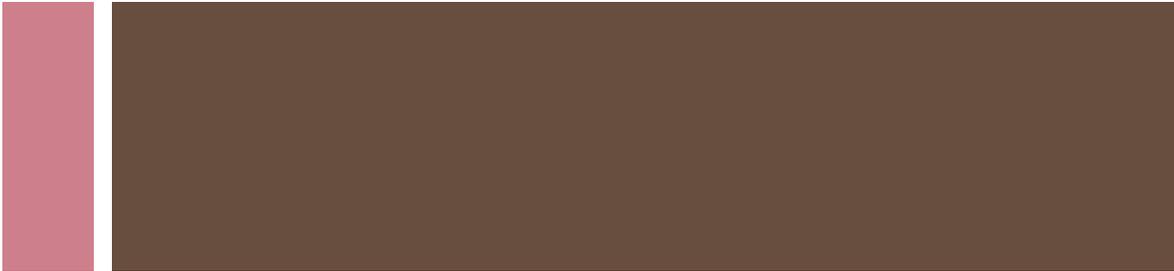
*What will the organisation do to empower people with disability and families and assist in the process of 'imagining better'?*

*How will the organisation empower front line staff so that they bring forward ideas and take on new roles?*

*What obstacles need to be removed so that person centred thinking can be incorporated throughout the organisation and so that respectful partnerships are built with people with disability and families?*

*How will the organisation establish a culture which is supportive of the long-haul needed to bring about change which reflects true person centred approaches and thinking?*

*What can happen in the shorter-term so that the potential for success is established?*



## Essential elements

The information gained from all sources point to a number of essential elements which need to be addressed in the change process. These were depicted in Figure 2, and are listed briefly here. They are:

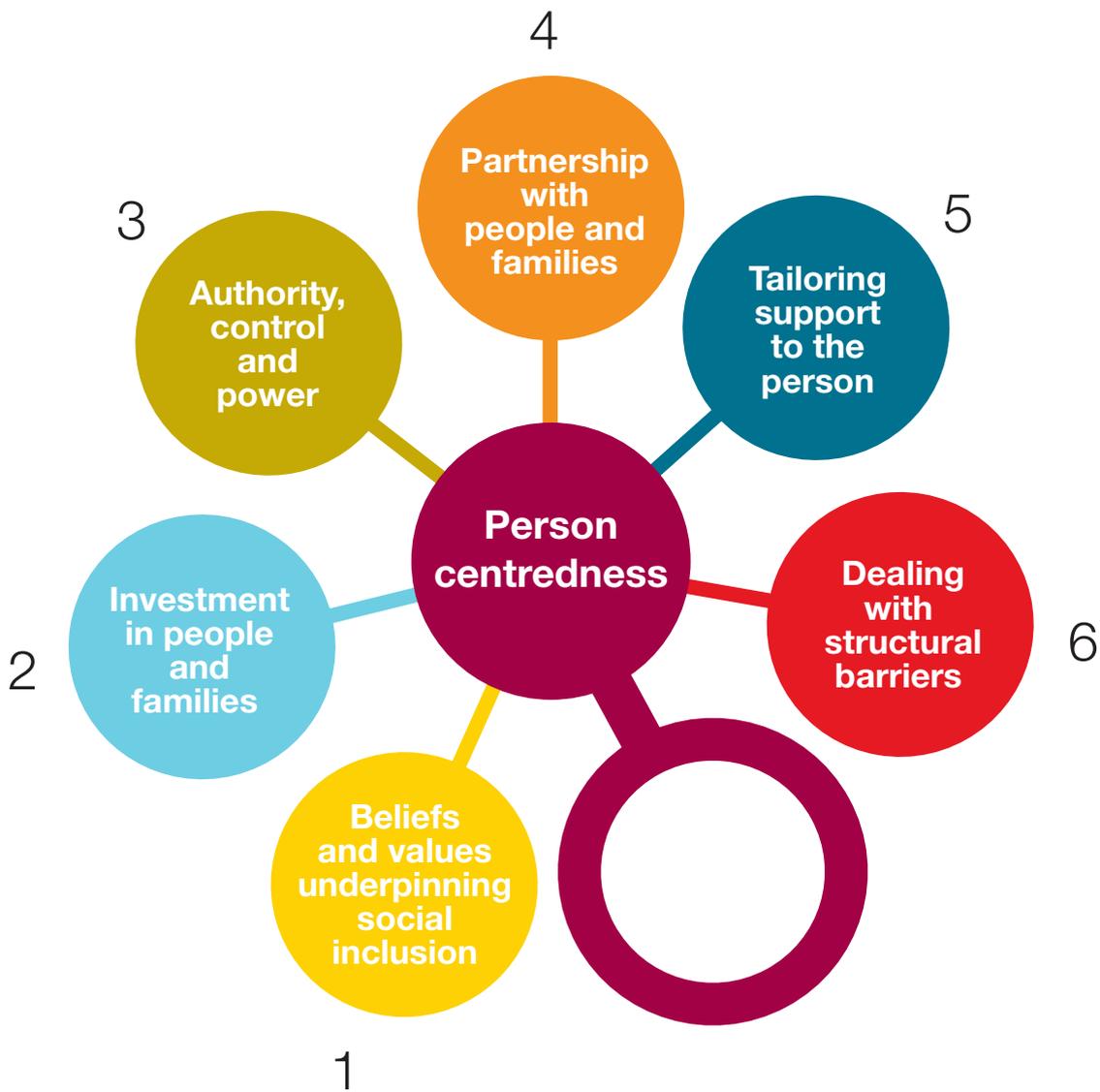
- hold beliefs and values in the organisation about people with disability and their right not only to be physically present in the community, but to fully participate in community life and to belong
- invest in people with disability and families
- enable a shift in authority, control and power
- enter into genuine partnerships with people with disability and families or allies
- truly tailor support to individuals
- deal with structural barriers.

This part of the guide is structured so that each of the 6 essential elements contains:

- an overview of issues relevant to the content
- implications for service providers
- evaluative statements which will assist an organisation to reflect on their status with regard to person centred approaches
- ‘Food for Thought’. These are ideas, suggestions, and questions which may help service leaders and staff think about what actions they could take.

The complete reflection exercise can also be found in Appendix 1.

These elements cannot be considered in isolation, rather they all have to be considered and addressed together.





*“When we use the term ‘person-centred’, we mean activities which are based upon what is important to a person from their own perspective and **which contribute to their full inclusion in society**”*

*Helen Sanderson*

## Beliefs and values underpinning social inclusion

International and Australian experience, writings and learnings stress the interconnectedness of person centredness and full inclusion in society.

***“Person centred planning means a move from service life to community life.”***

***(NSW Community Participation service provider)***

This statement shows a clear understanding that the key outcome of person centred approaches is to enable people to have ordinary and meaningful lives in the community, like people of a similar age, gender and culture.

***Peter is a man who said that he would like to follow his interest in fishing. Typically the service provider would arrange for him to go fishing with a group of other people with disability and one support worker – usually once a month although this couldn’t happen if the centre was down on staff. The other people in the group had not identified that their passion was fishing, rather they were happy to go along for the trip.***

***This did not enable Peter to enjoy social inclusion, the valued role of ‘recreational fisherman’, nor did it expand his networks and friendships. Along with Peter, they worked on a different strategy.***

***A support worker who has similar interests and was recruited because he is a good ‘connector’, has assisted Peter connect with a recreational fishing club in his locality. The support person’s role is to assist the other members of the fishing club become comfortable with Peter and how he communicates. The goal is that Peter will be able to be picked up by one of the club members and go fishing without a support worker.***

***The service provider allocates Peter’s funding differently. They recognise that it will be used more intensively for part of the year and will even out over the whole period as he is supported through freely given relationships.***

***(NSW Community Participation service provider)***

This interconnectedness is reflected in the NSW Community Participation Program Guidelines 2006. Building on world-wide knowledge and practice, they were developed by a group representing all stakeholders over a significant period of time. They spell out **principles** and the **key result areas** which are intended to be used by service providers to address the social exclusion and lack of power typically experienced by people with disability and families. The principles and key result areas underpin person centred approaches and thinking. Those which are relevant to the beliefs and values underpinning full inclusion are reproduced in a summarised form below:

### **Principles of the NSW Community Participation Program**

Person centred

Genuinely inclusive

Flexible

Culturally competent and respectful

Working in partnership

Responsive to people in rural and remote areas.

### **Key result areas/outcomes for people being supported through the Community Participation Program**

Maintain and develop everyday skills and increase independence

Continue to learn and participate in meaningful leisure, social and cultural activities

Participate and be included in the local community

Active and valued roles in the community

Expand friendship and support networks

Fair access for young Aboriginal people and those from culturally and linguistically diverse backgrounds



For the principles and key result areas of the Community Participation Program to be achieved, a shift is needed in how people with disability are perceived.

*“When power holders – whether professionals or family members – persist in seeing people in discouraging ways, desirable personal futures become difficult to achieve indeed.”<sup>9</sup>*

Many people with disability and families have not experienced the benefits of true social inclusion, full community participation or enjoyed a variety of valued roles in the community.

Parents may have come to believe that only specialist disability workers or organisations will look after and protect their sons and daughters, rather than there being both paid and unpaid people who care. When disability service providers provide their sons and daughters with the support needed for them to genuinely participate in the life of the community, families are able to see the difference and are more able to pursue these opportunities.

In addition, because of the level of disability, service providers and families might not have high expectations of some people participating fully in the community. It is evident though, in Australia as well as overseas, that there are many people with very significant support needs who are living ‘a good life’. They are living in their own homes, they are working or engaged in vocational training and some have started home-based businesses. They are involved in many social and cultural opportunities in their own communities. What it has taken is high expectations on the part of everyone involved and the commitment to provide the support needed in different ways.

### **Implications for Service Providers**

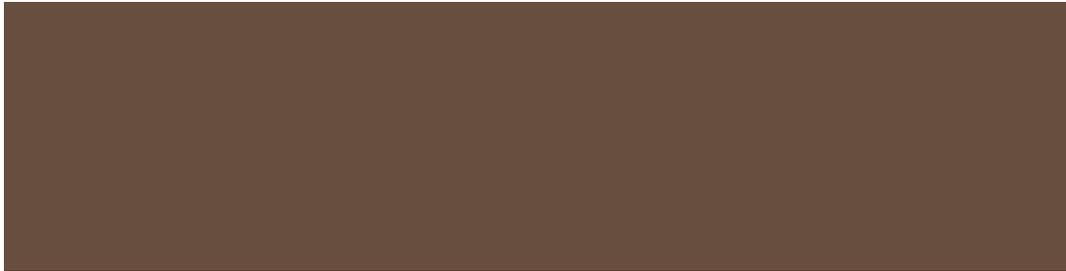
*“It is so easy to change the language without changing the structure or the culture.”<sup>10</sup>*

Research and evidence shows that person centred planning will achieve full inclusion and active and valued roles in the community when its complexity is recognised and acted upon. Scott Ramsey<sup>11</sup> suggests that planning has to place greater emphasis upon the importance of social contribution, intentional relationship facilitation, valued roles, disproving negative stereotypes and introducing a more critical thought base into the process.

9 O'Brien, J. & Lovett H. (1992) Finding a Way Toward Everyday Lives, The Contribution of Person Centered Planning, <http://thechp.syr.edu>

10 O'Brien, J. (1997) cited in Sanderson et al, *People, Plans and Possibilities*, Edinburgh: SHS Ltd.Planning, <http://thechp.syr.edu>

11 Ramsey, S. (2007) Roles Based Planning: A Thoughtful Approach to Social Inclusion and Empowerment, *The SRV Journal*, 2 (1)



He has proposed that ‘roles-based’ planning is more likely to holistically pursue valued roles by intentionally considering a number of aspects, including:

- environments
- associations/people and contacts
- activities which reduce stereotypes
- enhancing the person’s communication
- active and passive learning mechanisms.

It is also possible that people employed by service providers will respond by saying that this is just another thing required of us by the Government/bureaucracy. This is not necessarily the case. All around the world, there are service providers which realise that social inclusion, the achievement of valued roles, expanding typical networks and friendships are the right thing to do and will bring about significant change for individuals, for their families and for the broader community.

Without a deep understanding of the beliefs and values which underpin social inclusion and a willingness to ensure that these guide the organisation’s relationship with people with disability, person centred planning will falter and social exclusion and poverty of life experiences will continue for people with disability.

A man who has experienced social isolation when he attended a day centre, and who now relishes a more ordinary life, said:



***[Inclusion is that] “We’re not sat outside just because we have a disability... [so what he does is] just seeing how other people without a disability are living, and seeing how I can bring that into my life.”***

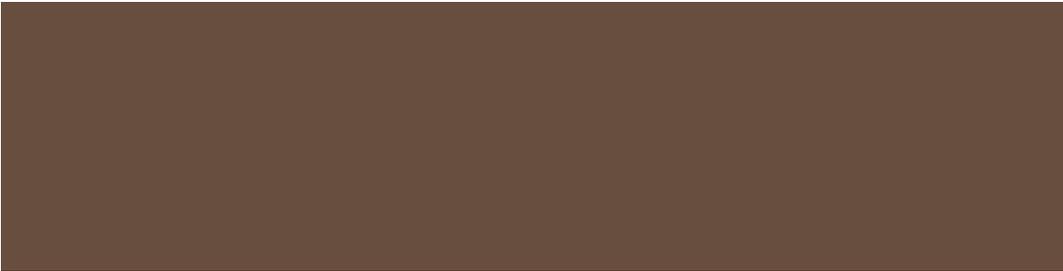
***(Person supported through a NSW Community Participation program)***

Service providers need to ensure that they have a strong understanding of social inclusion and that the beliefs and values that underpin social inclusion are strongly embedded in their organisation. Those which have adopted a culture of questioning, reflecting and reviewing realise the importance of a clearly understood value system which is based on responding to the person as a human being with unique interests, gifts, contributions and aspirations.

## Reflection Exercise

The following exercise is intended to assist service leaders and staff make a determination of the organisation's current stage of development. For the entire reflection exercise, please see Appendix 1.

Please give each statement a rating which most closely reflects your assessment	Low	High		
The lives and roles of people using your services mirror those of other ordinary members of the community.	1	2	3	4
People with disability are pursuing their individual interests in ordinary community groups and facilities.	1	2	3	4
The support provided does not reinforce stereotypical myths that are held about people with disability (e.g. they belong in specialist service settings, always need paid support).	1	2	3	4
Service personnel understand the importance of social inclusion and valued roles.	1	2	3	4
People with disability and families understand the importance of social inclusion and valued roles.	1	2	3	4
Service personnel believe that social inclusion is possible and desirable.	1	2	3	4
The organisation is structured to facilitate and enable social inclusion.	1	2	3	4



## **'Food for Thought' - Beliefs and Values Underpinning Social Inclusion**

The following is a list of suggestions, action steps, ideas and questions relating to beliefs, values, mission and vision. Some will involve long-term change strategies.

### **Organisational and cultural change strategies**

- *Examine, review and clarify the understandings of all levels of the organisation about the beliefs and values which underpin social inclusion.*
- *Develop a clear vision of what the values and beliefs will mean for the organisation's operations, action, language and relationships.*
- *Ensure that internal and external 'messages' consistent with a clear set of beliefs and values, are given frequently and consistently.*
- *Create opportunities for all levels of the organisation to understand what social and community inclusion actually means in practice.*
- *Examine stereotypical beliefs about various groups and individuals that may hinder person centred approaches.*
- *Recognise and respond to the diversity within cultural groups.*
- *Examine vision and mission statements, policies and practices in the light of a deeper understanding of social inclusion.*
- *Encourage internal discussion about whether the people currently served are experiencing genuine social and community inclusion.*
- *Ensure that the values of social and community inclusion are not misinterpreted.*
- *Ensure that everyone in the organisation, from board level to front line staff, understand that the principles and key result areas of the Community Participation Program Guidelines reflect current world wide practice.*

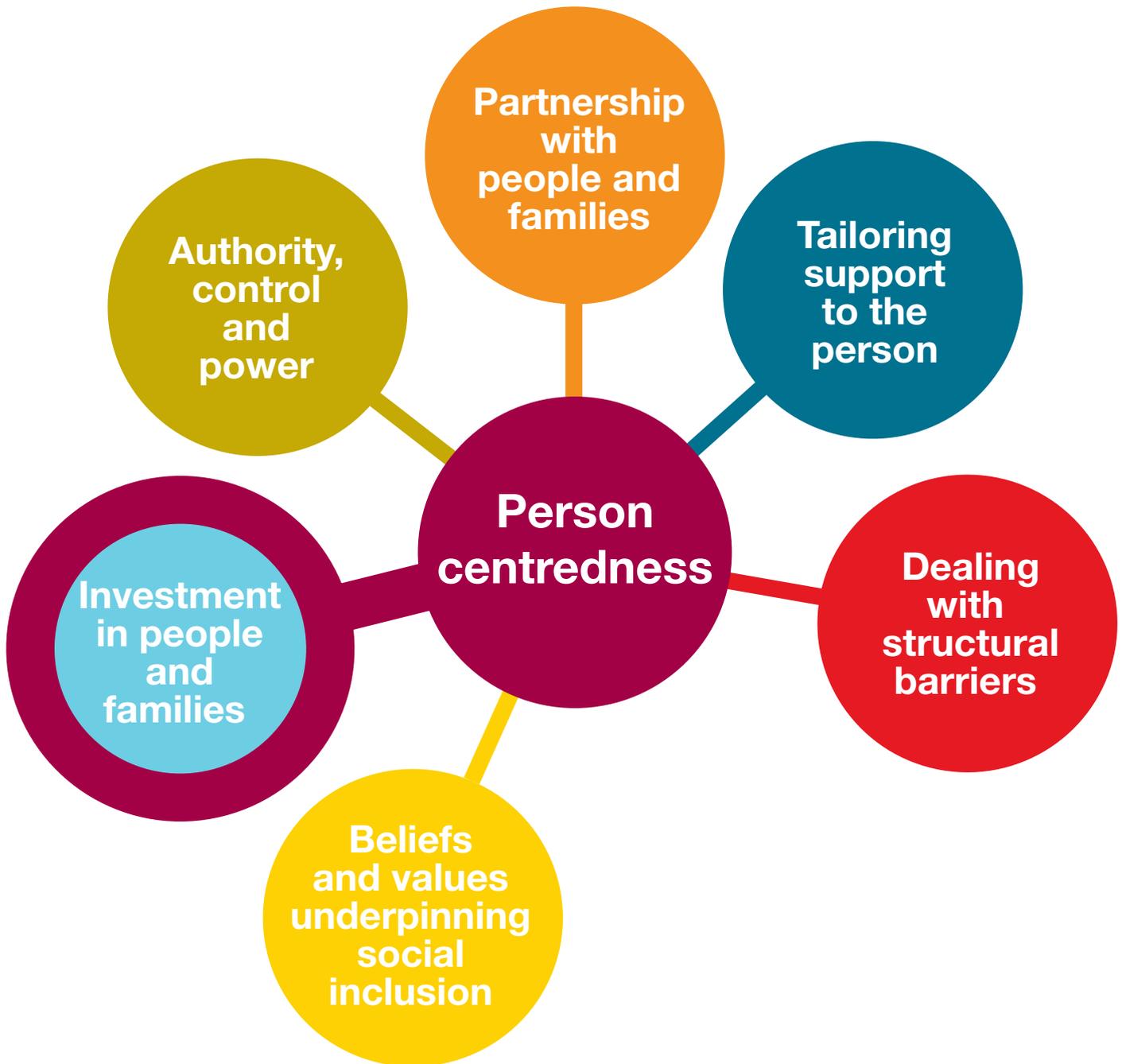
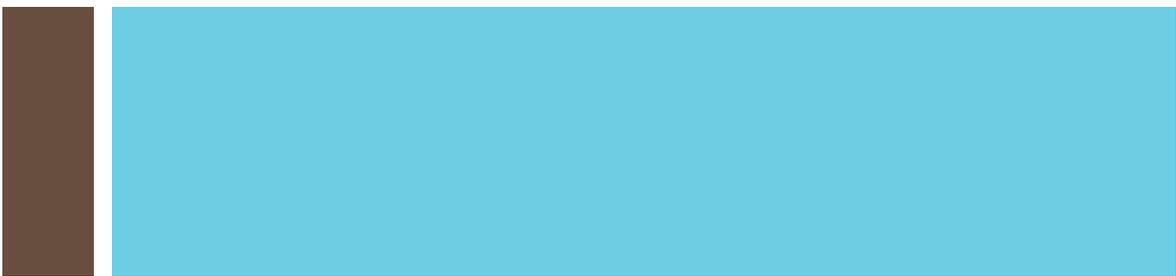


## Training, education and review strategies

- *Have experienced trainers and educators run in-service events about social and community inclusion across all levels of the organisation, including people with disability and families.*
- *Explore a wide range of opportunities to reinforce person centred thinking*
- *Build a culture of reflection, questioning and review.*
- *Recognise that training in itself will be insufficient and so create opportunities for deeper understandings at a practical level.*
- *Ensure that Board members and senior people participate in values-based training.*
- *Join with other like-minded organisations to establish a local 'community of learning'.*
- *Open the organisation to values-based review and evaluation.*

## Operational strategies

- *Investigate and use approaches and planning tools which truly address social exclusion and lead to social inclusion, valued roles and expansion of relationships and friendships.*
- *Recruit people who are committed to social inclusion – make it an essential criteria.*



*“People are enabled to move forward when they have a vision of ‘better’.”*

*Michael Kendrick*

## Investment in people and families

There are many people and families in NSW who have developed a vision of 'better' lives.

This has happened through the efforts of some service providers, but mainly through intentional leadership development projects conducted by independent family-based agencies. Gatherings of families and conferences over many years have been places where people with disability have shared exciting and inspiring stories, those of people moving into their own home, and people with very significant and complex needs leaving school having personalised and individualised support in many aspects of their lives. Families with school-aged children who have insisted on an inclusive education (in the regular classes of local neighbourhood schools) are creating a different demand on service providers.

It is vital to ensure that people with disability and families have opportunities to what Michael Kendrick often refers to as 'imagining better'.

***“A lot of work needs to be done in family development. The use of mechanisms like circles and other tools should only happen after development has happened for families.... Where they can see the ‘zone’, that is ‘have the vision’. The ideas and concepts need to come from families not top down mechanisms.”***

***(Parent of an individual supported through a NSW Community Participation program)***

Barriers do exist such that families and people with disability may not have an understanding of what social inclusion means, how to expect services to be person centred, or even about the option of enacting greater authority in their own lives. Even with understanding, some families and individuals might not have the resources such as confidence or social networks to act on this understanding.



## Challenges for people with disability

Some of the barriers to people with disability being able to engage in thinking differently include:

**The effect of the disability.** This may mean that the person may not be able to make informed choices or understand the consequences of choice making. They may not be able to picture a socially inclusive life and valued roles without support and ideas from people who know them well and who can ‘imagine better’.

**Lack of inclusive life experiences.** It is highly likely that most people with significant disability in NSW will have only experienced a life of segregation. Apart from life with their own families, they will have no experience of real social inclusion and the benefits this brings to their lives. They are more likely, therefore, to have low expectations about the possibilities social inclusion offers. If people have no experience, they will not be able to easily express a different vision of their future.

**Material poverty.** When most people with disability reach early adulthood, it is probable that they will receive a disability support pension which is lower than the minimum wage. They have had little experience and opportunity to think about a ‘typical life’ and things may just appear to be ‘pie in the sky’.

**Isolation and congregation.** Many people will not have experienced constructive and ongoing relationships with members of the broader community. They only know a life of being with other people with disability.

**Expectations.** They may not have people in their lives to assist with envisaging a different life. They may have become conditioned to the low expectations of being ‘cared for’ and ‘managed’ rather than supported to have a life. Many people have been conditioned to expect a life of activities and leisure rather than vocational training, study, skill development and work.

## Challenges for families

In addition, there are many barriers for families which will affect their gaining a vision of ‘better’ and an understanding of genuine person centred approaches and planning. These barriers have to be understood and recognised so that they can be addressed by service providers. They include:

**Dependence.** Many families have come to rely on services and professionals to have the ‘answers’. This will mean that families may be likely to avoid opportunities to voice their opinion or have their views tested. They may have come to believe that they don’t have any ideas to offer. Some may never have been asked by a service provider to provide their own ideas



about the future, about an ordinary life, and have that acted upon. As a result they may have come to believe that they don't have any ideas to contribute.

**Conditioned by experience.** It can be very difficult for families to have a vision of an inclusive, more positive future. They may be easily able to say what it is they don't like or want. What they don't know is how it could be different. Too often, people with disability and their families have not had opportunities to dream about the future in a positive way. Their thoughts about the future are often clouded by insecurity and anxiety. They may have had to compromise and have come to believe that they should just accept what they are offered and settle for less.



***“There is a huge gap! We have not put anything into assisting families to understand what person centred planning and social inclusion really mean. It was totally missed by the organisation and we are now experiencing the gap and the difficulties that this has caused.”***

***(NSW Community Participation service provider)***

**Time.** Many parents are both at work and/or have other children or young people they are caring for. Many are single parents who have to work.

**Stress and anxiety.** Many parents and brothers and sisters live a life of stress and frustration at having to deal with the gaps in services, the inflexibility of services, and this often brings about a lack of motivation to make change happen.

**Lack of Trust.** Families of adults may have grown used to being “called in” to do planning only to find that little changes. This will lead to lack of motivation and interest. Mistrust is also brought about by a fear of the unknown.



***“For some families, their involvement in planning has been so narrow that they can't imagine a wider vision.”***

***(NSW Community Participation service provider)***

**Lack of confidence.** Families may have little experience of being respectfully asked, or given alternative information, or put in touch with other families whose sons or daughters are being supported to enjoy social inclusion. They may be fearful that they will be thought to be incompetent and make mistakes.



**Language and cultural barriers.** For families who are from different cultural backgrounds, there could be language and cultural barriers which will have to be acknowledged and accommodated. Disability is conceptualised and responded to in different ways by some cultural groups.

The findings from international literature, from other examples in Australia of person centred approaches, and experience generated through the introduction of self-management in the NSW Community Participation Program has shown that when parents and individuals are freed from the constraints of *'this is what we offer and there is nothing else'*, they actually have much to offer, are highly motivated and are able to 'imagine better' as well as express it. It is also the case that, while they are very clear about what they do not want or like for their son or daughter, they need ideas, support and advice to think about how life could be different.

### **Implications for service providers**

It is for service providers, families and individuals to consider how to strengthen their understanding and resourcefulness. An organisation which is committed to person centred approaches will need to place itself in a position to invest in time, leadership development, information, education, the development of trust with people and families and to let them know that they are serious about a different way of providing support.

Investment in people and families therefore means a very different way of deploying resources. It could also mean that different resources have to be found. Service providers may have to partner with others to provide opportunities for people with disability and families to learn more about person centred planning.

When investing in people with disability and families, service providers will have to ensure that, particularly where a person has a very significant level of disability, they give time and information to families and to others who know the person well and encourage them to contribute to ideas and goals for a desirable future.

## Reflection Exercise

The following exercise is intended to assist service leaders and staff make a determination of the organisation's current stage of development. For the entire reflection exercise, please see Appendix 1.

Please give each statement a rating which most closely reflects your assessment	Low	High
The organisation understands the barriers which exist for people and families in being able to 'imagine better' and develop a positive vision for the future.	1	2 3 4
The service provider assists people and families understand the benefits and practical examples of genuine inclusion and valued roles.	1	2 3 4
There is commitment to sponsoring and supporting people and families to attend workshops, conferences and events where families and people tell inspirational stories of change.	1	2 3 4
The concept of support and planning circles is understood and there is commitment to assist these develop independently of the service provider.	1	2 3 4
It is a priority of the organisation to engage in leadership development opportunities for people with disability and families.	1	2 3 4

## **'Food for thought' - investment in people with disability and families**

The following is a list of suggestions, action steps, ideas and questions relating to investing in the development of people with disability and families. Some will involve long-term change strategies.

### **Organisational and cultural change strategies**

- *Acknowledge and recognise that there are long-standing barriers for people with disability and families in taking on decision-making and believing they have something to offer.*
- *Consider how service providers play a part in these.*
- *Have investment in families as a central strategic direction for the organisation.*

### **Training, education and leadership development strategies**

- *Provide developmental opportunities for families and individuals, such as supporting them to attend existing family conferences, or holding inspiring information sessions hosted by the agency.*
- *Expose the families and individuals to positive stories, so that they can 'see and believe'. These stories can be oral or written.*
- *Consider how the resourcefulness of each family might be expanded. For example, some families have found that having a circle of support has strengthened their capacities to 'imagine better' and to pursue good options.*
- *Connect families and individuals to those who are a 'bit further down the track'.*
- *Ensure board members participate in training.*
- *Contract with trainers and educators to run information events for families on person centred approaches and planning.*
- *Intentionally outreach to young people and their families who are still at school and start the investment process well before people are looking for services.*



## Operational strategies

- *Ensure that plenty of time is spent with the person and their families exploring different ideas and building up trust.*
- *Start small – find people and families who express an interest in trying something different. Once the individual with disability is engaged in socially inclusive opportunities and roles, ask the person and family if they would be prepared to speak to others.*
- *Adopt an approach that, when significant change has occurred for a person and their family, they will be the best people to assist other parents step forward.*
- *Allocate a budget to investing in people and families.*



*“Person centred planning is not simply a collection of new techniques to replace individual program 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.”*

*Helen Sanderson*

## Authority, control and power

Person centred thinking shifts the power from professionals to the person and their family. No organisation 'owns' the person's life – the person and their family does.

***“Person centred means a person at the centre, and saying ‘this works for me’. It’s like a machine going around. All of the pieces work together as they go around the core.”***

***(Person supported through a NSW Community Participation program)***

*“It sounds so simple. Read logically, it makes sense to us. ....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 approach will we truly be able to practice in a person centred way and understand the implications of our actions.”<sup>12</sup>*

***“A big difference for me is that, for the first time, people actually listened to me.”***

***(Person supported through a NSW Community Participation program)***

Assuming power and control could be difficult for families and individuals if they have not experienced having power before. It is not a familiar position for people with disability and families to find themselves making the decisions about their future. Additionally, their cultural background may make it particularly difficult for them to assume authority.

In the main, they have been taught to look to professionals, believing that being 'trained' in disability means that they always have better ideas and suggestions.

<sup>12</sup> Kilbane, J. & Thompson, J., (2004) 'What' and 'How': Understanding professional involvement in person centred planning styles and approaches. *Learning Disability Practice*, 7 (4), 16-20



Many people with disability and families, nevertheless, hunger for opportunities to have a real say. They may not initially express it but, given support and confidence, they say that they want their sons and daughters to be treated and respected as individuals, as people who can learn and develop, and as people others in the community can, with the right support, get to know and with whom they can form positive relationships.

They will need to have good information and exposure to others who are exercising control to enable them to assume authority and decision making. There are many people with disability and families in Australia and in NSW who have been given such opportunities and to whom authority, decision making and control through partnerships and relationships have been delegated by service providers.



***“We (the family) manage the program. We’ve set up what we know works and the staff member has added her flair and enhanced it.”***

*(Parent of an individual supported through a NSW Community Participation program)*

***“It’s 50/50. We’re not over each other.”***

*(Person supported through a NSW Community Participation program explaining how recruitment of staff was shared)*

Some families who have sons or daughters with high support needs have entered into written agreements with organisations which spell out each party’s roles and responsibilities.



***“We are developing agreements with individuals and their families which identify who will take responsibility for areas such as planning, advertising, recruiting, interviewing, risk management and supervision. These agreements look different for each person depending on what it is they want to do. They also take into account areas where the family or person needs skills and knowledge to take on more of the roles and responsibilities.”***

*(NSW Community Participation service provider)*

## Implications for service providers

Giving up power and control can be daunting for all levels of staff – from board members, senior management to clinicians and front line staff. It means professionals need to avoid a sole reliance on their professional training and to avoid offering only what is currently available from their menu of service responses. Instead it means listening to the person and the family about a more desirable lifestyle. Managers and board members may be concerned that responding to the desires of people will bring the budgets into deficit. Clinicians may interpret a person's aspirations as unrealistic. Direct support workers may not feel they have the skills to support a person to fulfill a valued and active role in the wider community because their experience has developed only through supporting people in a day centre.

All these concerns will have to be dealt with as people and their families are enabled to become the drivers – making the important decisions over the direction of their own lives.

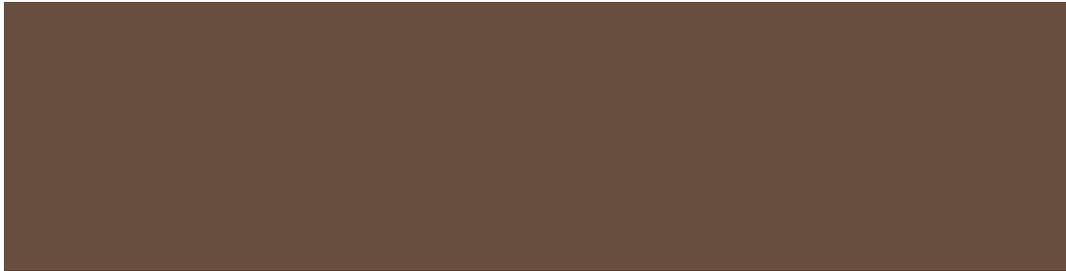
***“My service provider said I could have a lot of control over what my daughter did during the day. I found though that they did nothing. There was no plan, no implementation and no support for her.”***

***(Parent of an individual supported through a NSW Community Participation program)***

The roles of the organisation and the professional will change to become one of *‘what do we have to do to achieve this’*, not *‘what programs do we have which the person will be able to slot into’*. It will be difficult to learn new ways of assisting people without recognising that people have legitimate authority in their own lives and will make good decisions when given good information.

***“One family borrowed books from us, and they decided on the process they wanted and ran their own show.”***

***(NSW Community Participation service provider)***



Those working in the organisation will have to rethink their role from that of 'power over' to 'power with'.

*"Power over others is the most common and familiar form of power. People expect its use, feel uncomfortable in its absence, fear uncertain consequences of denying it, and easily fall back on it in time of stress. But power over others poisons the relationships necessary to support people with disabilities in taking their rightful places in community life."<sup>13</sup>*

Humility will be needed so as to enable a move in attitude and culture from 'What can **we** do for this person?' to 'What makes sense for this person and family?' 'What is it that this person wants for themselves and how can we help?' In addition, when this ethic is paired with the values of social inclusion, this changed way of thinking will be reflected in the language that is used. An example of this change of language which would symbolise a change of culture would be:

***'He got a job with a local business'***

***not***

***'We got him a job in open employment'***

An essential element in person centred approaches is addressing issues of power and control. Where professionals and managers have recognised the importance of individuals and families assuming authority and decision making over their own lives and have supported this to happen, a shift of power has occurred.

<sup>13</sup> O'Brien, J. & Lyle O'Brien, C., (1997) cited in Sanderson et al, *People, Plans and Possibilities*, Edinburgh: SHS Ltd.

## Reflection Exercise

The following exercise is intended to assist service leaders and staff make a determination of the organisation's current stage of development. For the entire reflection exercise, please see Appendix 1.

Please give each statement a rating which most closely reflects your assessment	Low		High	
Board, management and staff understand their role of enabling people with disability and their families to have control over their own lives.	1	2	3	4
The organisation has taken steps to learn about how other service providers have found ways to enable people with disability and families to exercise authority and decision making.	1	2	3	4
People with disability and families are supported and encouraged to drive their own plans for a desirable future.	1	2	3	4
The behaviour of service users and their families reflect their belief that they are in a power sharing relationship with the organisation (e.g. families are confident to put forward ideas for an inclusive future)?	1	2	3	4
The support arrangements reflect each person's cultural context, aspirations and values?	1	2	3	4
The policies, procedures, newsletter and other communication mechanisms reflect and enable authority, power and control to be shared with service users and their families.	1	2	3	4
The organisation is structured to facilitate and enable social inclusion.	1	2	3	4

## **'Food for Thought' - Authority, control and power**

The following is a list of suggestions, action steps, ideas and questions relating to sharing power and authority with people with disability and families. Some will involve long-term change strategies.

### **Organisational and cultural change strategies**

- *Explore and clarify the changing role of the organisation as one which is supplementing and enabling the person's life not controlling and managing it.*
- *Seek advice and support from other service providers who have embarked on the path of changing the position of power and authority to see how it can be done.*

### **Communication strategies**

- *Explain the direction to people with disability and families, assuring them that seeking their increased control and decision making does not mean that the organisation will stop supporting them.*
- *Identify and bring in external families and people with disability who are exercising authority and decision making over their lives to speak to families, people with disability and staff at all levels.*
- *Ensure that everyone understands that, with this changing role, the organisation and its staff are still very important but in different ways.*
- *Assist employees to see that their skills can be used in different ways.*
- *Spend more time with people with disability and families providing them with the opportunities to learn how they might exercise more authority and power.*



## Training and education strategies

- *Ensure that families and people with disability are given opportunities to understand the importance of social inclusion, valued roles and expanded relationships.*
- *Contract with external trainers and educators to work directly with people with disability and families.*
- *Enable people with disability and families to attend relevant conferences – ensure that they understand the issues of taking on power and have the potential to take on leadership roles in the organisation.*
- *Intentionally choose the conferences on which resources are going to be expended.*

## Operational strategies

- *Engage in re-training of staff.*
- *Be prepared to redeploy staff who, after support and supervision, remain unwilling or unable to share power.*



*“.....we have no automatic right to participate in planning with people. It is something that we have to earn through our relationship with a commitment to the person whose plan it is.”*

*Peter Kinsella*

## Partnership with people and families

'Partnership' infers that all parties have equal status. For service providers to enter into a partnership with a person and their family, they will need to develop a culture in their organisation which reflects this.

*"Person centredness lives in people and not in service or bureaucratic systems. It is something that begins within people and radiates outward to others."*<sup>14</sup>

Lack of trust and disappointment can be present in the relationship between service providers and those receiving support. People and their families may have much to say which is negative about service providers. Similarly service providers may have much to say which is negative about people and families. What surprises all parties is that the way they feel about the other is often the same. The following statements have been heard from both service providers and from people or their families about each other:

***They never have any time for me/us.***

***They have no understanding of what things are like for us.***

***They always want something different.***

***They treat me as if I don't care.***

***They don't realise the limitations on us.***

***They don't understand the funding.***

***They don't communicate with me/us.***

***They are never prepared to change.***

A realisation of this may be a starting point for both service providers and people and their families who want to have a different type of relationship and to enter into genuine partnership with each other.

A genuine partnership will mean that, while the person and their family will be the authors of what they want in the future, the service provider's role will be to negotiate how they will assist to attain the goals. This way, when there are priorities to be set, or even compromises to be made on the implementation, this will be done respectfully between the parties.

<sup>14</sup> Kendrick, M., When People Matter More Than Systems, cited in Cornell University, Person Centered Planning Education Site, <http://www.ilr.cornell.edu/edi/pcp>

***“If the family doesn’t have a vision, we start with the person’s likes and dislikes and go from there. As they see what can be, they show more interest. It is important for families to see and hear from other families.”***

***(NSW Community Participation service provider)***

A commitment to acting in partnership will mean that, over time, the person and their family and the service providers will have very different shared experiences of each other which will be positive and expressed in the following ways:

***We listened to each other and understood where we were both coming from.***

***They understand what things are like for me.***

***We will try something different together and work on it until it is right.***

***We both know what the level of funding is and what it can cover.***

***We are communicating with each other in a positive way even though we do not always agree.***

Michael Kendrick<sup>15</sup> identifies some common signs that demonstrate that a partnership is both ethical and fruitful. They are:

- truthful communication – *meaning that those in partnership should always try and remain truthful in their words and conduct, even though they will not be without fault*
- the partnership is transparent – *meaning that everything is ‘out in the open’*
- there is constant dialogue and relationship – *meaning that the partnership has to be actively pursued by both parties and that people with disability and families are not excluded from any relevant or important information*
- promises made are promises kept – *meaning that commitments made are acted on. If things do not happen for whatever reason, then this needs to be discussed and negotiations made about what happens next*
- there is a focus on the real issues in people’s lives – *meaning that the priorities or constraints of the service provider are a hurdle to overcome but do not take over*

<sup>15</sup> Kendrick, M. (2008) The Key Ingredients of Optimal Partnerships between Service Users and Families and their Possible Human Service System Partners, unpublished

- there is authentic sharing of power – *meaning that the service provider maintains a serious commitment to recognising the voice of the person with disability and their family*
- there is acknowledgement of failings and limitations – *meaning that both parties own up to each other about their shortcomings or changes of minds.*

Being treated and respected as partners will mean that families and people will not view themselves as ‘troublemakers’ and families will not feel as though they are getting in the way of a person having a good life. Their knowledge and interest will be recognised and respected. A true partnership will mean that there will be differing opinions and an ethical partnership will ensure that these are discussed openly and agreements reached.

Given that some people may not be in contact with their families for a number of reasons, it could be that, as the concept of ethical partnerships is understood more widely, some who might have been alienated in the past will regain involvement with the life of their son or daughter. Families will become a resource with many untapped connections and resources and they won’t feel they have to wait to be asked in – they will be empowered to set their own agenda.

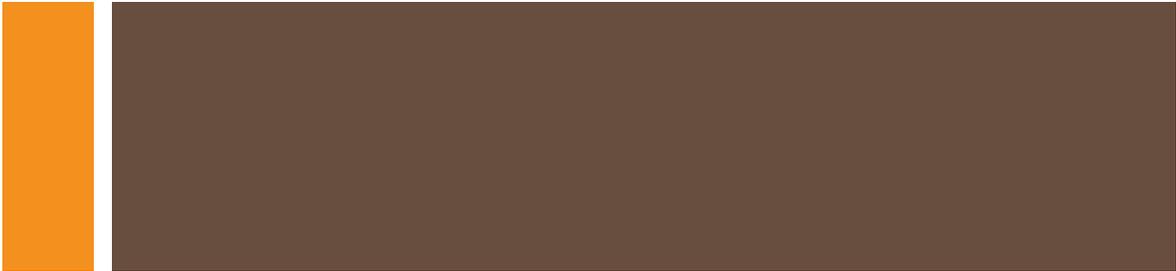
### Implications for service providers

Partnerships will become possible when service providers do not hold a stereotypical view of people as ‘clients’. When this occurs, the dominant view will be a change from *‘they need us as professionals to do their thinking for them’* to *‘we can work together as a team’*.

Partnerships will also become possible when the differences between ‘choice’ and ‘informed choice’ are examined and a clear understanding is reached about the pre-requisites which need to be in place for informed choice to be made.

***“I went and looked at the centre based service and thought ‘no way’. I didn’t see any reason for everyone being together. They were doing things that I knew he wouldn’t want to be doing and he would be bored. Because he can’t speak he needs to make choices by default. We need to try lots of things, see what he likes and pursue that.....he couldn’t have that flexibility at the centre.”***

***(Parent of a person with high support needs supported through a NSW Community Participation program)***



The relationship has to shift from being ‘in charge’ to ‘planning with’. In order for this to happen, people with disability need time to gain confidence, given that their main experience has been one of being told what to do and having others make decisions for them.



***“We aim to work in partnership. We listen to the expertise of the family around the person and we talk about the roles they can play and the decisions they can make. The service does the administrative tasks, such as reporting, finance and payroll.”***

***(NSW Community Participation service provider)***

Developing strong working relationships with families needs to take account of, and be responsive to, the cultural and social context of each person and their family. Care will need to be taken to ensure that dominant stereotypes and assumptions of cultural groups do not influence the organisation’s actions in working with families. For example, some cultural groups and Aboriginal people may conceptualise disability differently to the mainstream culture. There may be different family and kinship relationships and responsibilities that need to be recognised and supported. It is therefore important that person centred approaches are culturally secure and developed in partnership with individuals, families and their communities.

In addition, a greater understanding of the vulnerabilities of people with disability and their social situation will ensure that the views of professionals will not always dominate those of individuals and their families.

In order to respond to the vulnerability of people with disability and families in relation to their relationship with a service provider, care and attention should be paid to the planning itself. A true partnership approach will ensure that planning is carried out in an environment where people with disability and families are able to speak their minds, express their thoughts with greatest confidence, and be given many opportunities to experience and think about a different way of being supported. If the professionals doing the planning with individuals are also responsible for the service being provided this will undoubtedly reinforce vulnerability and lack of real choice.

***“We found a facilitator who could help us get our ideas together and he was also able to give us ideas on other people to contact who were being supported in very different ways. We couldn’t have talked about the things we did if my daughter’s service co-ordinator was doing the planning with us.”***

***(Parent of a person supported through a NSW Community Participation program)***

In order to enable a person and family to be in a position to dream and envision a different future and different roles, the person facilitating the planning process should be independent of the direct service provision. In addition, some families and individuals may want to do their own plans with no service involvement although they may need information and skills about how to go about it.

A genuine partnership will also be demonstrated through loyalty by the service provider to the person, come what may. Service providers have to embrace the notion that:

- all people can have a good life
- things are likely to go wrong even with the best of planning and culture change
- if things do go wrong, that they will stick by the person.

***“We can’t expect them (the service) to come up with all the ideas. We also need to do so and we are, in fact, encouraged to do so.”***

***(Parent of an individual supported through a NSW Community Participation program)***

Shifting the balance of authority, power and control is difficult for all involved, however with goodwill it can occur. With experience, support and trust, families are the best people to be making decisions with their sons and daughters (not for them) particularly when that person’s disability is a barrier to informed decision making. The service provider, working in partnership with the person and family, will be acting in a genuine person centred way.

## Reflection Exercise

The following exercise is intended to assist service leaders and staff make a determination of the organisation's current stage of development. For the entire reflection exercise, please see Appendix 1.

Please give each statement a rating which most closely reflects your assessment	Low	High
There is frequent dialogue and relationship building between service leaders and staff and people with disability and families.	1	2 3 4
Senior managers have made themselves aware of examples where service providers are working alongside people and their families to achieve valued roles and full participation in the community.	1	2 3 4
Invitations are extended to people and families to participate in key strategic planning, reviews and evaluations.	1	2 3 4
The planning and support arrangements respond to individual's cultural and linguistic background.	1	2 3 4
Planning with people and their families is conducted by workers who are not responsible for the service currently received from the organisation.	1	2 3 4

## **'Food for thought' - partnership with people with disability and families**

The following is a list of suggestions, action steps, ideas and questions relating to building and maintaining partnerships. Some will involve long-term change strategies.

### **Organisational and cultural change strategies**

- *Ensure that there is a belief throughout the organisation that people and families can work together.*
- *Include a person with disability and family member in any leadership group established to oversee the cultural and organisational change.*
- *In making the invitations to leadership groups, provide information to people so that the goals and objectives of the leadership group are understood by all.*

### **Education, training and review strategies**

- *Undertake intentional education programs and mentor staff to empathise with, and be aware of, the lack of ethically based partnerships that families will have experienced over a long period of time from professionals and others.*

### **Building partnership strategies**

- *Spend time with family members, friends and allies so that they are confident to join in the planning process.*
- *Ensure that meetings organised with families and people with disability are conducted in a family-friendly way in terms of times and locations.*
- *Join with like-minded others to attract and fund independent planners so that people with disability and families are empowered to develop a vision and plan for their own lives.*
- *Ensure that the cultural background of each individual is taken into account and responded to in any actions to support the involvement of families.*
- *Develop relationships and work with the specific cultural communities and leaders to which people with a disability may belong.*
- *Join with individuals and families in problem solving and dealing with barriers.*

### **Operational strategies**

- *Establish a specific team within the organisation to stimulate the cultural change needed for true partnerships to emerge.*
- *Redesign current positions so that there is capacity in the organisation to help people plan independently but with effective facilitation.*



*“When support arrangements are intentionally developed around the unique identity and needs of a person, it is much more likely that they will get more of what they need and their needs will be better met.”*

*Michael Kendrick*

## Tailoring support to the person

Person centred approaches mean that the organisation and professionals change from saying *'this is what we do'* to *'what can we do which will support you to do what you want to do?'*

It is, of course, much easier to offer prearranged activities and programs than to listen and tailor the support required but, to be truly person centred there is no alternative than to start from scratch. Tailoring support does not equate with tinkering with, or altering, existing program based activities to accommodate a person.

There are many organisations worldwide which have transformed themselves to tailor support to the needs of the person. Some of these agencies, which began with typical group responses, have been doing this for over 20 years and have not blown their budgets. In fact, they can demonstrate cost effectiveness as they are providing what is a good 'fit' and therefore 'good value for money'. Those who have been most successful have generally started small. This has enabled a process of learning from mistakes and building on successes. It has enabled the organisation to more easily create change for other individuals.

One of the principles of the NSW Community Participation Program Guidelines is 'flexibility' which highlights the need to cater to changing needs and skills.

Some service providers have enabled more personalised, tailored support while under more traditional funding regimes and others have achieved change when individuals have received individual support packages.

***Nidhi is young woman with a number of strong talents and passions that include arts and crafts and singing. She also has a number of disabilities and is supported through a centre based community participation program in a major rural city.***

***To pursue Nidhi's art interests the centre employed an art teacher to work once per week.***

***The service liaised with the Conservatorium of Music for a scholarship and now she goes there once per week for singing lessons. During an interview, Nidhi confirmed how much she loves this and said she had talked to the centre manager about doing more singing and song writing.***

***The centre arranged for Nidhi to take a craft class at community college out of which an idea emerged for Nidhi to start a small business making and selling craft kits for baby quilts. She now spends one afternoon making the kits and sells them through word of mouth but the centre is going to help her find other avenues to sell them, such as markets or local craft shops.***

***“Making the kits was a suggestion of someone here. I thought I’d give it a crack and I love it.”***

***(Nidhi, an individual supported through a NSW Community Participation program)***

### **Implications for service providers**

In NSW, the Community Participation Program is based on a system of individualised funding. While there may be constraints in how this is used by service providers, the system nevertheless lends itself to service providers being able to tailor support and be flexible about how they allocate resources. Individual funding in and of itself does not guarantee high quality, or that person centred approaches will be used but it is an opportunity on which to capitalise.

While each individual's funding allocation in NSW goes to a service provider decided upon by the person and/or their family, service providers need to acknowledge that, unless they create a very different way of working with the individual, this serves to reinforce their more powerful position.

*“Without control of the resources, the goals of person centered plans remain entirely at the discretion of those who typically provide service and support.”<sup>16</sup>*

It is a mechanism which can be used creatively by service providers. Individuals and families should be provided with the information about what their level of funding is and what it can provide so that they can enter into negotiation about how it might be used to respond more flexibly to their goals and aspirations.

16 Nerney, T. (2005) Self-Determination After a Decade, *TASH Connections*, April/May



In order to be in a position to tailor support, there will also be a need for different recruitment strategies. Staff will need to be employed on the basis that they hold similar interests and have the capacity to act as community connectors for individuals. Paid staff may be engaged in getting to know community leaders, church, synagogue or mosque leaders, leaders and significant people in community organisations, community colleges, hobby and interest groups and other associations. They might be employed to scour the local newspapers, newsletters and the internet to source potential connections in the wider community.

Support worker roles will change. They will need to start to think of themselves as, and be supported by their employers to become, personal assistants, business assistants, guides, drivers, interpreters and facilitators.

Organisations will have to be prepared to organise the support flexibly. For example someone might need a high level of staff intensity as they begin to participate in new roles in the wider community. This will mean that staff may have to change the hours they work for a particular period of time. They may have to be available in the evenings, or at weekends. If, for instance, a person has indicated that they would like to be a singer and wants to join the local choir, they may need help to get there in the evening for practice and rehearsals.

Tailoring support to the person means significant changes to the ways that most organisations operate and how staff carry out their roles. Without discovering the ways that the organisation can tailor the support to people, person centred approaches cannot be achieved.

There are several planning tools which can help with tailoring support and these are summarised in Appendix 2.



### Reflection exercise

The following exercise is intended to assist service leaders and staff make a determination of the organisation’s current stage of development. For the entire reflection exercise, please see Appendix 1.

Please give each statement a rating which most closely reflects your assessment	Low	High		
The service response to each person is unique.	1	2	3	4
The administrative processes track expenditure for each individual and provide regular reports to individuals.	1	2	3	4
Staff are recruited to work with a specific individual, based on desirable characteristics such as shared interests.	1	2	3	4
Rosters are shaped around individuals, with high degrees of flexibility.	1	2	3	4
Generic community resources are identified and used to support an individual with a disability.	1	2	3	4

## **'Food for thought' - tailoring support to the person**

The following is a list of suggestions, action steps, ideas and questions relating to tailoring support. Some will involve long-term change strategies.

### **Operational strategies**

- *Be prepared to re-examine how each individual's approved level of funding can be used so that the organisation is able to act on its commitment to person centred approaches and plans.*
- *Look into ways whereby people can exercise maximum authority over their own money.*
- *Look at ways to 'stretch' the funding by considering community resources, informal supports and negotiating administrative costs if people and families are prepared to take on agreed roles.*
- *Explore ways to recruit staff differently and find ways for people and their families to recruit staff.*

### **Communication strategies**

- *Work with the person and family on their priorities.*
- *Ensure the person and family know about their funding level and what it can be used for. Help them build their plan.*

### **Education, training and review strategies**

- *Bring in resources to train, develop and support staff in their new roles.*
- *Develop skills in the service to maximise independence of people with disability.*



*“When applied in bureaucratic organisations, person centred planning has met the same fate as other professionally controlled interventions.”*

*Jim Mansell*

## Dealing with structural barriers

Organisational structures, policies and practices play a vital role in whether or not person centred approaches and planning are successful. The research, writings and interviews with NSW service providers identifies some common barriers which will typically have to be addressed. These include:

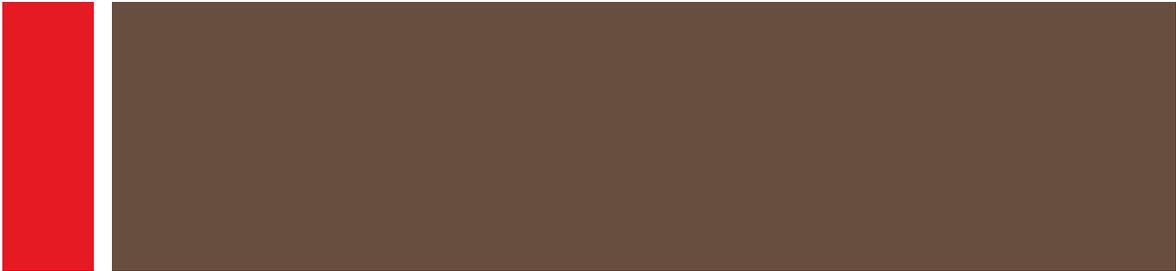
- a belief that change to person centred thinking can be made rapidly and simply
- a top down structure where the leadership is far removed from people, families and direct support
- a reliance on predictability and standardisation
- oriented to the present
- high levels of control over the actions of staff
- resistance
- size
- believing that the organisation has to provide everything.

### Implications for service providers

**Pace of change.** It is crucial for the organisation to embark on the cultural and structural change necessary **at the same time** as some people are being supported to think and plan. Even more, it is incumbent on the organisation to set itself up to be able to respond so that they do not end up with everyone doing plans but there being no capacity in the organisation to respond effectively.

***“We found that we invested too much at the planning level and not enough at the cultural change level. In the beginning, our key performance indicator was that we would have a large number of plans completed. We realised it was totally wrong and would lead to disaster so we threw it out and started again. We were in danger of having engaged people in planning but not being able to deliver. We changed to a parallel strategy – organizational, cultural and structural change at the same time as planning with a smaller number of people. We need the engagement with people to drive the changes necessary, just as much as we need a different culture to be able to deliver.”***

***(NSW Community Participation service provider)***



The leadership must create a climate throughout the organisation that the change process will take some time. Additionally, change has to be managed through a twin approach of cultural and structural transformation as well as enabling people with disability and families to experience a different way of thinking about the future.

Often, the plan that emerges for a person from real listening and from a foundation of trust and partnership will be about long-term goals, so the organisation has to be committed to maintain a changing role over time.

*“Person centred planning involves the individual with disability, along with their family members, friends, and other important people in their life. Through a series of discussions, they develop a personal plan. This plan looks to the future, usually covering a span of three to five years, although it can be longer.”<sup>17</sup>*

**Organisational structure.** The structure will need to enable good communication and have the capacity for speedy problem solving with others in the organisation, the encouragement of new ideas, and incorporate an effective way of discovering what is not working. Senior people will need to get to know and understand the needs of the individuals being supported.

**Non-standardised responses.** Organisations which typically work on the basis that the person with disability will be fitted into a standard set of activities and programs will have to develop the capacity to respond to more complex and unpredictable circumstances. True person centred approaches will mean that individuals will be participating in and using services and supports which are not the responsibility of the service provider. These will include freely-given support brought about by the person getting to know a wider range of people.

Person centred approaches affect all the actions of an organisation. Typically all the policies, procedures, roles and responsibilities need to be examined to accommodate the flexibility and variety of situations in which people will be supported. The typical responses to legislative and bureaucratic requirements need to be re-examined. For example, because staff will be working in a wide range of environments and situations, it may be necessary to teach all staff how to conduct risk assessments and take responsibility to avoid risks rather than rely on designated staff to take on these tasks.

**Future Orientation.** Most of the planning which is done with individuals is about the past and the present. Person centred approaches and thinking call for a different perspective that puts a focus on the future.

<sup>17</sup> Northeast Alberta Community Board (2007) Transition Planning – a Guide for Families and Guardians of Individuals with Developmental Disability <http://www.pdd.org>

*“Person centred planning creates a compelling image of a desirable future and invites people to join with the person to make it happen.”<sup>18</sup>*

When people with disability and families are supported to be the authors of their own goals and aspirations, based on the person and a ‘real’ life rather than on their disability, it will inevitably mean that they will dream about a different future – where they might want to live, with whom they want to live, what they want to do, with whom they want to spend time, what interests they want to follow, and the valued roles they want to attain. If the organisation has not taken steps to change so that it can respond to the higher expectations which this brings, then they will inevitably not be able to deliver. Mistrust and frustration will set in.

Service providers committed to person centredness have found they have to embrace a new future for themselves and invest in people who are future oriented. They say that there is a need:

- to hold high expectations for everyone, irrespective of the level or nature of disability
- to look outside the organisation
- to develop the capacity to see barriers as something to be overcome and pushed through
- to develop capacity to create new opportunities
- for leaders who will champion and oversee the ongoing cultural change which person centred approaches bring
- to take stock of what it will take to become person centred
- for leadership which is prepared to invest time and energy in reflection and evaluation
- to re-examine the difference between leaders and managers. Service providers will need both but need to realise that leadership means making a difference. Managers are generally expected to manage what currently exists.

***“If a person needs something that we have not done before we just have to work out how we will manage it.”***

***(NSW Community Participation service provider)***

<sup>18</sup> O'Brien, J. & Lovett, H. (1992) Finding a Way Toward Everyday Lives, The Contribution of Person Centered Planning <http://thechp.syr.edu>

**Roles of Staff.** Another issue to be considered and implemented is fundamental change in the recruitment and roles of paid support staff. This includes:

- a change in the relationship between paid staff and the people they are paid to serve
- staff will become answerable to the person – they move from support worker to personal assistant
- a change in the nature of their work. More time will be spent on helping people make connections in the community
- a change in the way people are recruited. People will be recruited on the basis of matching a person's interests, or being a good community connector
- a change in the boundaries between work and personal life meaning that staff members can become a resource – thinking about people they know in their lives who might share interests with a person
- staff will have to learn how to do their job when others enter into the life of the person in freely given ways.

***“I want someone who:***

***- is different to a ‘carer’***

***- treats me like an ordinary person – treats me like I am the same as them***

***- knows the kinds of things I like doing in the ways I like doing them***

***- asks questions rather than making decisions for me, listens and pays attention to me. This means they wait for me to answer and say what I want.”***

***(Part of a list of requirements for a support worker, written by an individual supported through a NSW Community Participation program)***



**Resistance.** If there is a common and repeated theme in the organisation that *'we're already doing it'* and *'there's nothing wrong with what we are doing'*, then there may be a need for the leadership of the organisation to re-examine how they are managing the cultural change process.



***"It became clear that one of the managers was not committed to the new direction and this resulted in nothing happening for individuals as a result of the planning process. At the end of the day, the person had to go."***

***(NSW Community Participation service provider)***

Leadership will be required to deal with an attitude of *'We can't change what we do. There are rules that won't allow'*. There will need to be critical examination of whether the 'rules' are the barrier or whether all those responsible are thinking creatively enough.

**Size.** Experience shows that in order to be able to respond quickly to the individual needs of people, the decision makers in an organisation need to be 'close' to the service users. Services need to be able to respond and make decisions quickly about what an individual needs. When this is not part of a 'menu' of available options the service provider needs to be able to make decisions about allocation of funding and implications for policies and procedures. This may be achieved by keeping organisations to a small size so that senior decision makers are able to quickly respond or through the creation of quite autonomous units of service delivery with decision making capacity for budgets and policy implications.



***"I couldn't be at a size where I don't know the people supported and the staff.....We are part of a big organisation but we control what happens in our area. We know the people and make the decisions here."***

***(NSW Community Participation service provider)***



Providing Everything. Not only will service providers have to shift their relationships with people with disability and families, but they will also have to form new alliances and relationships with the local community and the variety of community agencies. They will start to partner with others outside the disability specialist environment to see what others can do.



***“Person centred organisations seek to play a part in the communities in which they work. They don’t seek to work in splendid isolation.”***

***“Adam’s passion is football and he wanted to have a role in a football club. A senior person in the day centre is very involved in a local football club. He negotiated a role of ‘assistant coach’ for Adam. Some people at the football club have now started to ask what they can do to assist Adam attend.”***

*(NSW Community Participation service provider)*

***“Networking is a huge thing; politicians, families, colleges. They all know things that can help. Don’t die wondering just ask someone. You have nothing to lose.”***

*(NSW Community Participation service provider)*

***“There needs to be a shift from rescuing. The organisation will have to face not being the be all and end all.”***

*(NSW Community Participation service provider)*

This section of the guide has highlighted the magnitude and complexity of addressing structural barriers. Whilst these may be formidable, research and practice has demonstrated that it is essential to address these issues in order to implement person centred practices. The same research and practice has also demonstrated that these barriers can be overcome.

## Reflection exercise

The following exercise is intended to assist service leaders and staff make a determination of the organisation's current stage of development. For the entire reflection exercise, please see Appendix 1.

Please give each statement a rating which most closely reflects your assessment	Low	High		
There is a deep and accurate understanding of the complexity of person centred approaches (compared to person centred planning tools) in the Board and senior management team?	1	2	3	4
There is at least one champion who could carry a cultural change process?	1	2	3	4
The organisational structure (or a preparedness to develop one) will facilitate partnering with families and individuals and engaging in individualised responses to people's needs and plans?	1	2	3	4
There is capacity in families and individuals to work in person centred ways?	1	2	3	4
There is capacity in existing staff to work in person centred ways?	1	2	3	4

## **'Food for thought' - dealing with structural barriers**

The following is a list of suggestions, action steps, ideas and questions relating to structural barriers. Some will mean long-term change strategies.

### **Organisational and cultural change strategies**

- *Continually ask 'are we doing the right thing? Are we responding?'*
- *Identify issues considered to be barriers.*
- *Establish an open culture which encourages discussions and new ideas.*
- *Develop strategies to bring everyone in the organisation along.*

### **Operational strategies**

- *Establish a leadership group – made up of the right people – which has carriage of the overall change.*
- *Carry out an 'audit' of the barriers and opportunities to embracing the change necessary to become person centred.*
- *Establish person centred development group(s) which have the capacity to generate ideas and problem solve.*
- *Review roles and responsibilities identifying where staff can make their work reflective of person centred approaches.*
- *Don't just tinker around the edges by introducing person centred planning as a substitute for current planning practices.*
- *Establish a structure that can work on the basis of one person at a time – start small.*
- *Consider the use of independent planners or facilitators.*
- *Provide information and skills to individuals and families so that they can start to create plans which will reflect their own goals and aspirations.*

### **Policy and practice strategies**

- *Review policies, procedures and practices so they do not hinder person centred thinking and planning.*
- *Establish a way of engaging in regular organisational renewal.*
- *Join with other organisations who are similarly engaged with a view to establishing joint projects relevant to organisational change strategies.*



## Education, training and review strategies

- *Review existing training and reshape it as necessary.*
- *Engage in sound and relevant training for all levels of the organisation.*

## Communication strategies

- *Develop ways of sharing information with families, community organisations, generic organizations and advocacy groups.*

## Conclusion

Achieving genuine person centredness, person centred approaches and thinking, and planning is vital for people with disability to enjoy a life which is socially inclusive and which provides opportunities for people to fulfill active and valued roles in their communities, expand their social networks and friendships and achieve their unique goals and aspirations for their future.

At the same time, it is challenging for disability service providers, for people with disability and for families.

*“In order to support the kinds of community changes necessary to improve people’s chances for a desirable future, virtually all existing human service policies and agencies will have to change the ways they regard people, the ways they relate to communities, the ways they spend money and the ways they define staff roles and responsibilities.”<sup>19</sup>*

As long ago as 1992, John O’Brien and Herb Lovett recorded ideas from a gathering of people experienced in various approaches to person centred planning. They summarised as follows:

Person centred planning can invite, align and direct shared efforts to create positive community roles for people with disabilities. It allows people who want to work for more inclusive, more just communities to exercise their practical wisdom and free themselves from the negative effects of a long history of segregation and coercive relationships. To support their work and its improvement, practitioners need to extend their network of relationships across the different approaches to person centred planning, community development and service reform. The future of person centred planning depends on their willingness and ability to improve their practice through critical reflection on the effects of their work in the lives of people with disabilities and their families.<sup>20</sup>

Insights from this gathering are just as current today.

19 Valuing People – A New Strategy for Learning Disability for the 21st Century – Guidance for Implementation Groups, <http://valuingpeople.gov.uk>

20 O’Brien, J. & Lovett, H. (1992) Finding a Way Toward Everyday Lives: The Contribution of Person Centered Planning <http://thehcp.syr.edu>



# Appendix 1

## Reflection Exercise

The following reflective exercise can be used by organisations to identify the opportunities and constraints to the organisational and cultural change required to embrace person centred approaches and thinking. A determination of your organisation's position will provide an overall visual snapshot. This snapshot can then be used to pinpoint where the organisation can advance person centred approaches and act as a starting point for the development of an action plan.

Each organisation's actions will differ. Some may choose to work on an area where existing strengths have been identified. Others may choose the areas where it is identified that there is a need for significant development. Yet others will make decisions to start where they see opportunities based on their current circumstances and context. It is in the hands of each organisation to move forward in ways that best suit them and the individuals they support.

The references and, in particular, the websites listed in Appendix 3 provide a valuable range of resources including a selection of links to specific evaluative tools. These will assist organisations further in developing responses to the challenge of developing person centred approaches and thinking.

Please give each statement a rating which most closely reflects your assessment.

1. Beliefs and values underpinning social inclusion	Low		High	
The lives and roles of people using your services mirror those of other ordinary members of the community.	1	2	3	4
People with disability are pursuing their individual interests in ordinary community groups and facilities.	1	2	3	4
The support provided does not reinforce stereotypical myths that are held about people with disability (e.g. they belong in specialist service settings, always need paid support).	1	2	3	4
Service personnel understand the importance of social inclusion and valued roles.	1	2	3	4
People with disability and families understand the importance of social inclusion and valued roles.	1	2	3	4
Service personnel believe that social inclusion is possible and desirable.	1	2	3	4
The organisation is structured to facilitate and enable social inclusion.	1	2	3	4

Please give each statement a rating which most closely reflects your assessment.

2. Investment in people with disability and families	Low	High
The organisation understands the barriers which exist for people and families in being able to 'imagine better' and develop a positive vision for the future.	1	2 3 4
The service provider assists people and families understand the benefits and practical examples of genuine inclusion and valued roles.	1	2 3 4
There is commitment to sponsoring and supporting people and families to attend workshops, conferences and events where families and people tell inspirational stories of change.	1	2 3 4
The concept of support and planning circles is understood and there is commitment to assist these develop independently of the service provider.	1	2 3 4
It is a priority of the organisation to engage in leadership development opportunities for people with disability and families.	1	2 3 4

Please give each statement a rating which most closely reflects your assessment.

3. Authority, control and power	Low		High	
Board, management and staff understand their role of enabling people with disability and their families to have control over their own lives.	1	2	3	4
The organisation has taken steps to learn about how other service providers have found ways to enable people with disability and families to exercise authority and decision making.	1	2	3	4
People with disability and families are supported and encouraged to drive their own plans for a desirable future.	1	2	3	4
The behaviour of service users and their families reflect their belief that they are in a power sharing relationship with the organisation (e.g. families are confident to put forward ideas for an inclusive future)?	1	2	3	4
The support arrangements reflect each person's cultural context, aspirations and values?	1	2	3	4
The policies, procedures, newsletter and other communication mechanisms reflect and enable authority, power and control to be shared with service users and their families.	1	2	3	4
The organisation is structured to facilitate and enable social inclusion.	1	2	3	4

Please give each statement a rating which most closely reflects your assessment.

<b>4. Partnership with people and families</b>	<b>Low</b>	<b>High</b>
There is frequent dialogue and relationship building between service leaders and staff and people with disability and families.	1	2 3 4
Senior managers have made themselves aware of examples where service providers are working alongside people and their families to achieve valued roles and full participation in the community.	1	2 3 4
Invitations are extended to people and families to participate in key strategic planning, reviews and evaluations.	1	2 3 4
The planning and support arrangements respond to individual's cultural and linguistic background.	1	2 3 4
Planning with people and their families is conducted by workers who are not responsible for the service currently received from the organisation.	1	2 3 4

Please give each statement a rating which most closely reflects your assessment.

5. Tailoring support to the person	Low	High
The service response to each person is unique.	1	2 3 4
The administrative processes track expenditure for each individual and provide regular reports to individuals.	1	2 3 4
Staff are recruited to work with a specific individual, based on desirable characteristics such as shared interests.	1	2 3 4
Rosters are shaped around individuals, with high degrees of flexibility.	1	2 3 4
Generic community resources are identified and used to support an individual with a disability.	1	2 3 4

Please give each statement a rating which most closely reflects your assessment.

<b>6. Dealing with structural barriers</b>	<b>Low</b>	<b>High</b>
There is a deep and accurate understanding of the complexity of person centred approaches (compared to person centred planning tools) in the Board and senior management team?	1	2 3 4
There is at least one champion who could carry a cultural change process?	1	2 3 4
The organisational structure (or a preparedness to develop one) will facilitate partnering with families and individuals and engaging in individualised responses to people's needs and plans?	1	2 3 4
There is capacity in families and individuals to work in person centred ways?	1	2 3 4
There is capacity in existing staff to work in person centred ways?	1	2 3 4

## Appendix 2

### Summary of ways in which planning with individuals can occur

***“The tools are useful but it is the (person centred) thinking that makes the difference.”***

***(NSW Community Participation service provider)***

There are many ways in which planning actually takes place, all of which share common features including that the planning takes place over time with continued listening and exploration of ideas. Regular reviews and meetings are part and parcel of the process ensuring that, as people’s confidence grows, as new opportunities emerge, and as new goals and aspirations are identified, so the support and the response of a service provider will change. Helping people to think in a person centred way often precedes the actual planning.

There are a variety of planning tools which can be used. Some of the better known are summarised below with information about their particular strengths and functions:

#### Personal Futures Planning

Personal Futures Planning involves getting to know the person and what their life is like now, developing ideas about what the person 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. Personal Futures Planning looks at the person’s life through 5 outcome areas and builds on what is working well, develops a vision of a desirable future and what it will take to achieve this.

#### Essential Lifestyles Planning

Essential Lifestyles Planning was developed for people with severe disabilities and was used with people moving out of institutions. It is a tool that looks closely at the person’s life now and it is a good tool for highlighting what is not working well at the moment. It does not examine 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.

## McGill Action Planning System (MAPS)

MAPS was first developed for use in planning inclusion for students in schools but is now used for adults. There is a focus on gathering information about the person, developing a 'dream' of the future while at the same time working towards the 'dream'. It has been noted that it is a good information gathering tool to be used in the early stages of planning. It also focuses on identifying the person's gifts and needs.

## Planning Alternative Tomorrows with Hope (PATH)

PATH is another person centred planning tool that develops a vision of a desirable future. It differs from MAPS in that it is designed for planning teams where the person can clearly describe their own 'dream', or when others who know the person well can more easily articulate this. It does not focus on gathering information in the present, but is a way of planning direct and immediate action.

Some organisations are incorporating person centred thinking tools into their everyday practices.

***“Our documentation is being replaced by processes that reflect a person centred practice framework. For example, we have used tools developed by Helen Sanderson. Learning logs have replaced shift notes. We use the ‘doughnut’ tool as part of the supervision framework. When we review, we use the relationship circle tool and the ‘what’s working/what’s not working’ tool.”***

***(NSW Community Participation service provider)***

The same organisation is cautious about the emphasis on tools and processes.

***“Some of the training provided is too ‘tools focused’. We are currently pursuing links with a variety of people overseas and in Australia to help us with critique, mentoring and support.”***

***(NSW Community Participation service provider)***



Planning with and for people with disability has evolved, however, since the above forms of planning were created.

### Roles Based Planning

Scott Ramsey<sup>21</sup> has identified roles based planning as a '*promising development with the disability sector in terms of helping people with disabilities become more valued and socially included within today's society*'. He notes that roles based planning was first conceptualised and implemented in Canada in 2001. Roles based planning, according to Ramsey:

- 1. starts with the dreams and interests of each person*
- 2. ensures that each person has been provided with sufficient information and direct experience to make informed decisions about their future*
- 3. applies critical thought to how each dream or interest can be pursued in ways that will help each person to be seen as a valued, contributing citizen and optimize their opportunities for developing friendships*
- 4. identifies and attempts to overcome the negative impacts of societal stereotypes upon people with disabilities*
- 5. identifies and responds to each person's most pressing needs and barriers to success as part of the planning process and*
- 6. shifts focus from filling time with activities to thoughtfully and thoroughly pursuing valued roles and relationships within the community.*

Further information about specific person centred planning tools can be obtained from websites listed in Appendix 3.

<sup>21</sup> Ramsey, S. (2007) Roles Based Planning: A Thoughtful Approach to Social Inclusion and Empowerment, *The SRV Journal*, 2 (1)

## Appendix 3

### References

The following guides, articles, guidelines, websites and books have been used to inform the development of this practice guide:

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Valuing People – A New Strategy for Learning Disability for the 21<sup>st</sup> Century. Guidance for Implementation Groups



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## Websites

There are a great many sites which are dedicated to, or contain, information and resources about person centred approaches. They are too numerous to include here. A selection follows, all of which contain links to other sites and resources.

[www.ilr.cornell.edu/edi/pcp](http://www.ilr.cornell.edu/edi/pcp) - Cornell University, Employment and Disability Institute: Person Centered Planning Education Site, USA

<http://rwjms2.umdj.edu/boggscenter> - The Elizabeth Boggs Centre on Developmental Disability, USA

[www.anti-marginalization.com](http://www.anti-marginalization.com) - Scott Ramsey, Canada

[www.kendrickconsulting.org](http://www.kendrickconsulting.org) - Michael Kendrick, USA

[www.neighbours-inc.com](http://www.neighbours-inc.com) - Neighbours Inc, USA

[www.family-advocacy.com](http://www.family-advocacy.com) - Family Advocacy, NSW, Australia

[http://www.melbasupport.com.au/one\\_by\\_one.html](http://www.melbasupport.com.au/one_by_one.html) - Melba Support Services - Family governed arrangements, Victoria, Australia

[www.in-control.org.uk](http://www.in-control.org.uk) - In Control, UK.

[www.self-determination.com](http://www.self-determination.com) - Centre for Self-Determination, USA

[www.parent2parentqld.org.au/planning/planning\\_index.html](http://www.parent2parentqld.org.au/planning/planning_index.html) - Parent to Parent Queensland, Australia

<http://www.inclusion.com> - Person Centered Thinking Resources, USA

<http://www.valuingpeople.gov.uk> - Valuing People, UK

[www.familiesleadingplanning.co.uk](http://www.familiesleadingplanning.co.uk) - Families Leading Planning, UK

[www.elpnet.net](http://www.elpnet.net) - The Learning Community for Person Centred Practices, USA

[www.circlesnetwork.org.uk](http://www.circlesnetwork.org.uk) - Circles Network - Building Inclusive Communities, UK

<http://thechp.syr.edu> - The Center for Human Policy, Syracuse, USA

[www.pdd.org](http://www.pdd.org) - Northeast Alberta Community Board, Canada

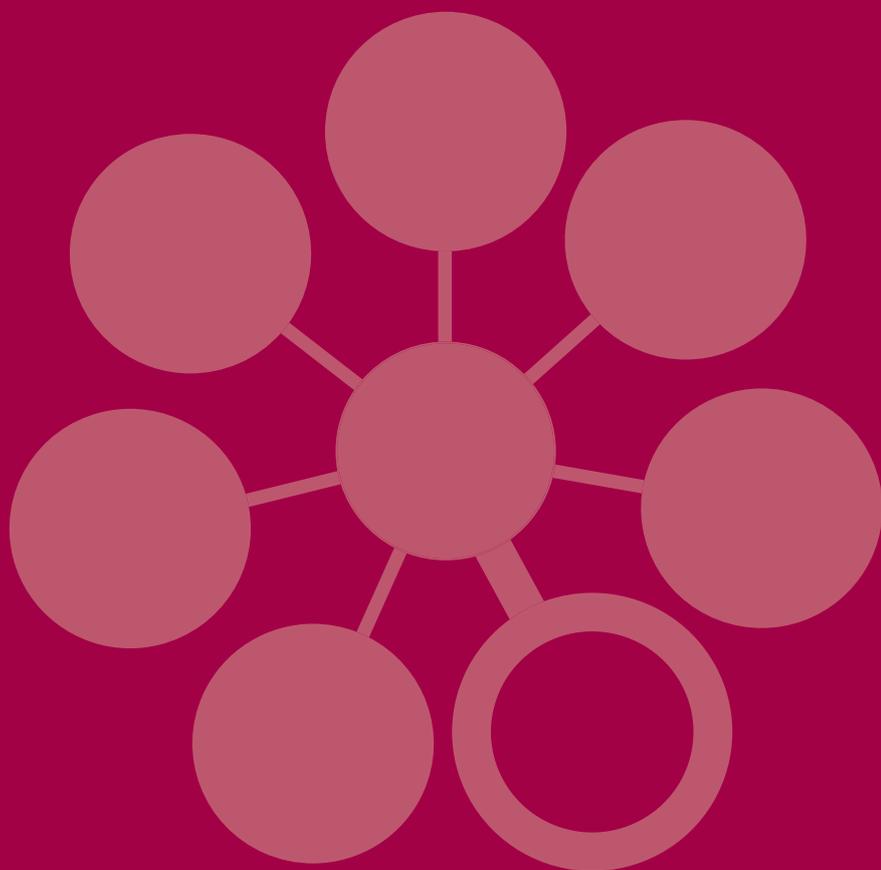
Listed below are three specific links relating to evaluative tools and checklists.

[www.valuingpeople.gov.uk/dynamic/valuingpeople139.jsp](http://www.valuingpeople.gov.uk/dynamic/valuingpeople139.jsp) - Person Centred Approaches: A checklist for Providers

[www.valuingpeople.gov.uk/dynamic/valuingpeople140.jsp](http://www.valuingpeople.gov.uk/dynamic/valuingpeople140.jsp) - Guidance for Partnership Boards including 'How Good is our Person Centred Planning Framework?'

[www.valuingpeople.gov.uk/dynamic/valuingpeople136.jsp](http://www.valuingpeople.gov.uk/dynamic/valuingpeople136.jsp) - 'Planning with People: Guidance for Implementation Groups', Chapter 8.





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