A Review of Best Practice in Individual Needs Planning

REPORT AUTHORS:

Leanne Parsons, My Place

Professor Errol Cocks, Curtin University

Monique Williamson, National Disability Services WA

March 2009

Acknowledgements

CONTENTS

PROJECT SUMMARY

The Individual Needs Planning (INP) Project resulted from collaboration between the lead agencies, *Nulsen Haven Association (NHA)*, *National Disability Services Western Australia (NDSWA.),* and Curtin University's *Centre for Research into Disability and Society (CRDS)*, which was engaged to conduct the project. The reference group for the project included a representative from each organisation and the Project Officer, Leanne Parsons from *My Place*.

The aim of the project was to investigate approaches to planning around the individual needs of people with disabilities in order to identify issues associated with good practice. The focus was on the approaches used by formal providers of accommodation services in Western Australia. Excellence in individualised planning can result in a range of satisfying outcomes for those involved, however achievement of excellence in this area has proved challenging.

The project used a number of qualitative methods appropriate to the range of stakeholders involved. A literature review was conducted to identify some initial themes and elements of best practice. A range of stakeholders in W.A. supported accommodation services was identified and their views were sought through written surveys, a number of case studies, and personal interviews. Using a qualitative research approach, the information gathered was analysed and the key themes and issues were identified. These themes and issues form the major findings of the project.

This project was made possible through the support of the WA Disability Services Commission which provided funding through the 2007 Quality Systems Improvement Grants scheme.

INTRODUCTION

OVERVIEW

Individual needs planning (INP), when used effectively, is an important strategy to improve quality of life outcomes for people with a disability. For over 25 years, various forms of INP have been used both within formal disability services and informally by individuals and families. Despite an ongoing commitment to INP throughout the disability field, difficulties with implementation are common. There are differing understandings about what constitutes 'best practice', and the connection between planning efforts and outcomes for individuals remains problematic. This project was developed in order to explore and clarify the use of INP processes in formal accommodation support services for people with a disability in WA, and to identify best practice principles in planning for the benefit of all who have an interest in this area.

BACKGROUND

The history of individual planning can be considered within the context and the history of service development and provision for people with disabilities. Until the middle of the twentieth century, services to people with disabilities were in the form of large, medically-based institutional models. These were inherently impersonal, entailing large congregations of people for whom segregation from society was considered appropriate. Planning, such as it was in this context, was concerned with the maintenance of order and daily routines.

In the 1950's and 1960's, parents of people with a disability began to envisage more for their family members and so parent-run organisations and support services emerged. In 1964, The WA Mental Health Services began a process of separating services for people with an intellectual disability and people who had a psychiatric disability, with a move away from the medical model to a more developmental model.

Service provision in the late '60s and '70s was still based on large institutions; however more positive assumptions regarding the ability of people with disabilities to grow and develop were gaining traction. As a result, an emphasis on training programs emerged, and in many cases individuals with a disability learned to do things previously not contemplated or thought possible. This raising of expectations

was also associated, in the late 1970's, with the early development of inclusive education, competitive employment, and community living. The focus on individualised planning during this period focused on the development of skills and the management of behaviour of people with a disability. In the 1970s and 1980s, many jurisdictions around the world enacted legislation mandating individual program plans (IPPs) that largely focused on skills and behaviour rather than broader issues of lifestyle. Early research pointed to issues of inadequate engagement of families in processes that were intended to be participatory and the manner in which IPPs became routinised and drawn into formal, system-serving processes and outcomes.

Many of the person-centred planning frameworks that are widely used today represented efforts to address these early problems by basing processes in explicit person-centred values. In addition to higher expectations and moves towards more inclusive forms of service provision, there was a reaction against the deficit model that had underpinned earlier planning regimes. The deficit model came to be seen as an approach whereby each person was essentially a collection of problems which needed to be fixed by identifying and working on the person's deficits. A strengths-based approach, explicitly described in early person-centered planning efforts, emphasised a person's strengths and aspirations, and was built on a set of positive assumptions concerning the rightful place of people with disabilities in their communities.

The development of INP over the past three decades has been influenced by a number of key developments in the disability field.

1. The emergence of *influential ideas and theories*. These have had a profound influence on our understanding of disability and on the service response to disability.

   - The Principle of Normalization (Nirje, 1969, 1980; Wolfensberger, 1972) and the subsequent development of the theory of Social Role Valorization (SRV) (Wolfensberger, 1983).

   - The concept of dignity of risk (Perske, 1972).

- The notion of least restrictive alternative/environment (Education for all Handicapped Children Act, 1975).

- The social model of disability (Finkelstein, French, Swain & Oliver, 1993; UPIAS, 1976).

2. The formation of *progressive movements* within the disability field, including community living, inclusion, and empowerment.

3. The worldwide phenomenon of institutional closure, which has been a long-running priority of disability policy. An enduring critique of deinstitutionalisation has been the extent to which it has been impersonal and that, for many, the options provided were no better or possibly worse than the institutions left behind. However, as already noted, some efforts did incorporate the development and use of person-centred, inclusive approaches, including Personal Futures Planning (Mount, 1992) and Essential Lifestyle Planning (Smull & Burke-Harrison, 1992) to determine the most suitable accommodation and lifestyle for the person.

4. The development of person-centred planning technologies, described as a "family of approaches to organising and guiding community change in alliance with people with disabilities and their families" (O'Brien & Lovett, 1992, p. 5). The most influential and enduring of these was a framework consisting of the five accomplishments: community presence, community participation, encouraging valued social roles, promoting choice, and supporting contribution (O'Brien, 1984).

5. An emphasis on individual choice, expressed through measures including the replacement of block funding with individualised, portable funding, and greater scope for individuals and families to govern or otherwise influence their service arrangements.

6. Influential people who have been passionate in their efforts around person-centred planning and provided necessary leadership, including John O'Brien, Connie Lyle O'Brien, Marsha Forest, Susan Burke Harrison, Herb Lovett, Beth Mount, Jack Pearpoint, Michael Smull, Judith Snow, Helen Sanderson, Pete Ritchie, and Jack Yates. Their ideas can be summed up in the following quotation:

    "Person-centered planning did not ignore disability; it simply shifted the emphasis to a search for capacity in the person, among the

person's friends and family, in the community, and among service workers. A person's difficulties were not relevant to the process until how the person wanted to live was clear. Then it was necessary to imagine, and take steps to implement, creative answers to this key question, 'What particular assistance do you need because of your specific limitations (not labels) in order to pursue the life that we have envisioned together (O'Brien, O'Brien & Mount, 1997, p.2)".

AIMS OF THE PROJECT

It is the experience of the project partners and of many other stakeholders in the disability sector that high quality planning around individual persons with a disability is difficult to identify, implement, and maintain, especially over the longer term.

Common difficulties include:

- The tendency of planning processes to become standardised and formalised, limiting the capacity to tailor processes and outcomes around individuals;

- Ensuring the participation of, and relevance for, all stakeholders;

- Harnessing the potential of planning processes to contribute to positive outcomes; and,

- Issues of relevance and renewal over the longer term.

Existing literature has identified processes of renewal as being central to continued high quality planning, however strategies for operationalising these are not widely known or implemented.

This project aimed to address each of these areas, with an emphasis on learning from those who are engaged in planning in a range of Western Australian service arrangements. The project ultimately aims to contribute to better outcomes for people with disabilities to which excellent planning contributes.

METHODS

The Project used three methodologies to gather information about INP processes in a sample of WA accommodation service providers for people with a disability.

 1. Literature Review

A review of national and international peer-reviewed and descriptive literature was undertaken. This occurred through internet and manual searches of descriptive literature, use of scholarly databases for review of peer-reviewed literature, and use of networks to access material not otherwise available.

2. Survey of Stakeholders

Through a scoping exercise of WA service providers of accommodation support, all funded organizations were identified and a survey instrument sent to all thirty nine organisations in Western Australia. In addition, seven organisations in other states of Australia, and two organisations in New Zealand were sent the survey. The survey instrument was designed to draw on their knowledge and experience, and seek recommendations regarding the processes they used for INP. The survey is included in Appendix A.

A total of 16 organisations chose to participate in the survey

3. Analysis of Case Studies

A sample of six service provider organisations that were considered to illustrate a range of approaches to planning for service users was selected. Surveys and personal interviews with stakeholders of these services were conducted in order to learn in more depth about their processes, outcomes, and strategies. After being invited and agreeing to participate, individual examples of INP were nominated by these organizations for case studies.

A brief description of these case studies follows:

Individual A: A teenager, sharing accommodation with five older adults supported by a non-government organization (NGO) in the metropolitan area. The family of the teenager lived in another Australian state and was unable to participate in the

interviews. The person, agency coordinator, and the agency staff were involved and interviewed.

Individual B: A primary school-aged child, sharing accommodation with five other people with disabilities, supported by an NGO in the metropolitan area. The mother of the child, agency coordinator, and agency staff were interviewed.

Individual C: A young adult living in a 'host family' arrangement, supported by an NGO in the metropolitan area. The person, the host family, agency coordinator, and agency staff were interviewed.

Individual D: A young woman living in her own rental unit supported by an NGO in the metropolitan area. The person, her sister, agency coordinator, and agency staff were interviewed.

Individual E: A woman sharing accommodation with four people with disabilities supported by a Government provider in the metropolitan area. The person, her father, agency coordinator, and agency staff were interviewed.

Individual F: A young man sharing accommodation with 20 other people with disabilities, supported by a Government provider in the metropolitan area. The person, his mother, agency coordinator, and agency staff were interviewed.

4. Integration of Findings.

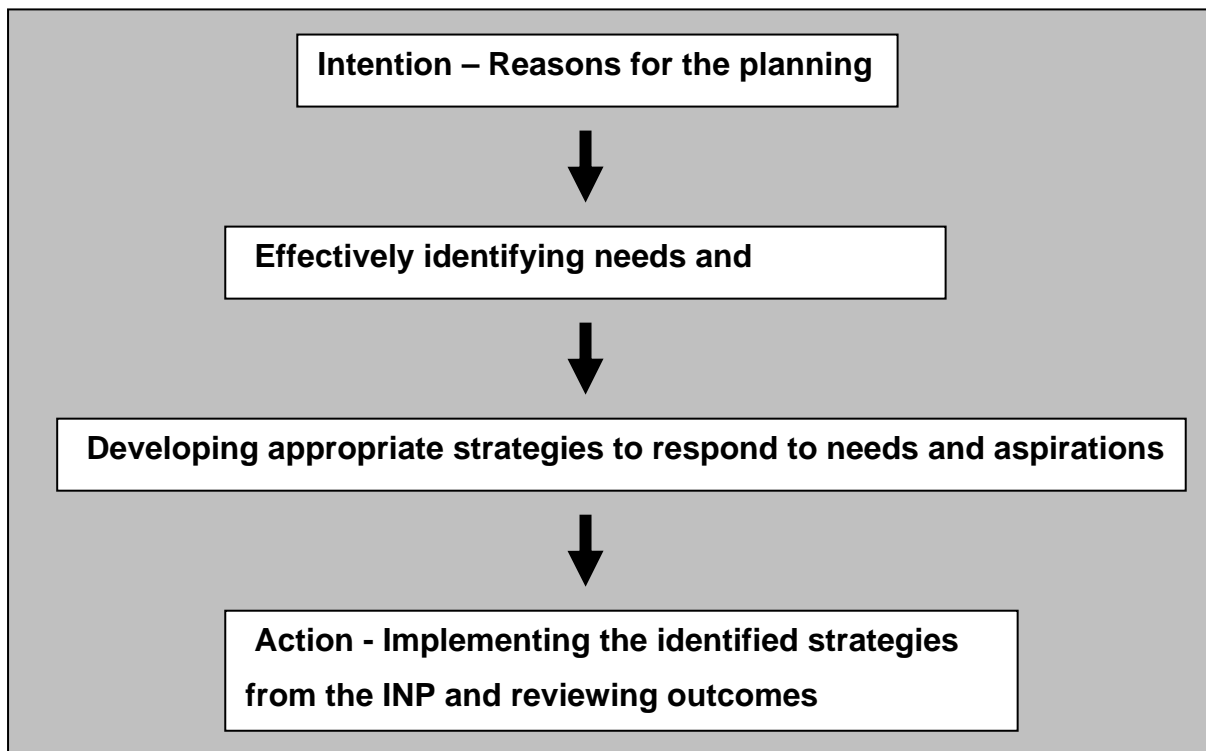A qualitative approach was taken in reviewing all of the information gathered and drawing out the major themes. The three main authors each independently reviewed project data to determine main themes. The authors met to deliberate and identified a set of ten themes and some additional issues. These themes represent a consensus of stakeholders' views about the key issues in individual needs planning.

INDIVIDUAL NEEDS PLANNING FRAMEWORK

The authors of this report developed a framework (Diagram 1) that can be used to conceptualise the overall process of Individual Needs Planning (INP). Each element of the framework will influence the next stage of the overall INP process. For example, where the intention or reason for the planning is to meet a policy requirement, people administering the planning may be less motivated to identify a person's real needs and aspirations. While none of these elements guarantee optimal outcomes from the planning process, each one can be considered, evaluated, and developed to improve INP. Each one paves the way to increase the likelihood that optimal outcomes will be achieved.

Diagram 1: INP Framework

Element 1: Intention – Reason for the planning

This element of the framework is the intention or aim of the planning. To achieve optimal outcomes from planning it is important that it is underpinned by the right intention. Ideally, planning should be approached with the intention to improve the life of the focus person. Other purposes can sometime drive the planning process,

for example planning undertaken because it is a requirement of the organisation's policy.

Element 2: Effectively identifying needs and aspirations

This element of the planning framework refers to effectively identifying the real needs and aspirations of the person. It refers to the capacity of those engaged in planning to understand and accurately reflect the real needs and aspirations of the person. It will require considering which needs and aspirations are more important to the person and/or require more timely action. A variety of processes could be used to identify needs and aspirations.

Element 3: Developing appropriate strategies to respond to needs and aspirations

Once needs and aspirations have been identified, it is critical that effective strategies are developed to respond to them. At this stage of the INP process, it is important that the strategies developed to meet identified needs are effective, i.e., the strategies are well-matched and likely to result in meeting the needs. It is also important that the strategy is reasonably likely to be achievable given current and future resources.

Element 4: Action - Implementing the identified strategies from the INP and reviewing outcomes

The final element in the INP process is action. The identification of needs and strategies are wasted unless appropriate action follows. Implementing the identified strategies and reviewing the person's situation over time increases the likelihood that planning will lead to optimal outcomes.

A set of nine key themes emerged from the analysis of information gathered. The background and key issues associated with each theme are described in this section.

Theme 1: A person-centred organisational culture

BACKGROUND

The planning style that was utilized during the 1970's was based on a perceived need for people to "qualify for progression to the next stage" or to remain in their present situation. Progression depended upon their skills levels which were often measured using standardized instruments. For example, in order to move from a small institution, to a hostel, to a group home, people with a disability had to have acquired greater skills. People had to "qualify" for community living. The plans and training goals were identified largely by the service provider, often using very detailed checklist-type approaches.

Influential ideas and theories began to emerge that challenged these assumptions by drawing attention both to the harmful impacts of congregation and segregation of people with a disability, and to the importance of people having access to the regular rhythms of life and valued social roles. The Principle of Normalization (Nirje, 1969, 1980; Wolfensberger, 1972) and the social science of Social Role Valorization (SRV) (Wolfensberger, 1983) became, for a time, the basis of policy and service development, as well as education and training. Ideas around a normal pattern of life and valued social roles gradually replaced the rigid emphasis on skills training. This move required that the life of the person with a disability be considered in a more holistic way, a central part of the emerging theme of person-centredness. The SRV Theme of *The Developmental Model* proposed that interventions in the lives of people with a disability should be *relevant* to their needs, and *potent* in their effectiveness.

The disability field has also been strongly influenced by the social model of disability. The social model drew more attention to the contribution of the environment in the creation of disability, particularly the limitations imposed by poor attitudes, policies, and practices in the shaping of a negative concept of disability. The balance of power between people with disabilities and the service provider shifted, creating

change in the way services were provided. The focus of services began to move from fixing the person to providing opportunities for people to participate in life, in part through addressing societal attitudes and barriers, particularly those imposed by the formal service system.

John O'Brien was influential in the Normalization and SRV movements as well as the move towards more inclusive forms of service provision. His work on planning is still widely used today, especially the planning framework consisting of the Five Accomplishments (O'Brien, 1984).

1. Community Presence

2. Community Participation

3. Encouraging Valued Social Roles

4. Promoting Choice

5. Supporting Contribution

Institutional closure formed an important backdrop to developments from the 1980's onwards. Early work in the process of people moving to a range of community living options included the use of planning approaches such as Personal Futures Planning (O'Brien & Lovett, 1992; Mount, 1992) and Essential Lifestyle Planning (Smull & Burke-Harrison, 1992) to determine the most suitable accommodation and lifestyle for the person.

The further development of person-centered approaches has emerged from an emphasis on the themes of inclusion and citizenship in all areas of service provision, particularly accommodation, employment, and education. Person-centered planning, defined as: "a family of approaches to organizing and guiding community change in alliance with people with disabilities and their families" (O'Brien & Lovett, 1992, p. 5), remains an important concept in ensuring the voice of each person is central to any service arrangement.

This Project identified the presence of a person-centred culture as the essential and most important element of an organization that contributes to successful INP.

KEY ISSUE

1.   <u>Service-focused and person-focused organisational cultures</u>

The concept of organisation culture comes from organisational theory. It refers to the unwritten rules, shared beliefs and values that drive an organisation and its staff. The organisation's culture influences staff behaviour and service practice.

Developing and maintaining an organisational culture that is genuinely person-focused requires considerable effort and ongoing assessment, reflection, and commitment to action.

Individual needs planning processes have tended to become standardised and formalised by organisations in a way that unintentionally limits the capacity to tailor processes around individuals, and has therefore become a service system process. Planning may be based on a standard document for all people, carried out in the same way for all people, and scheduled and managed for all people by the agency. This service system focus thus challenges the authenticity of the often-stated intention of individualised planning.

One service provider's response to the question: "How do you determine a person's individual needs?" was: "We ask them". This is a simple yet profound reply - as the interview developed, it was clear that the service provider's role was to design and develop service responses around the person's individual preferences and needs, with the person and/or family/representative as the natural authority to direct those services. The starting point was what the person wanted, and then responding and acting accordingly.

On the other hand, for some people, the intention of the planning was primarily about responding to a legislative requirement within a paper based, system-serving exercise. The individual was a client of the service and planning was done to, and not done with the person.

It was also noted that the practicalities and time constraints of scheduling the planning meetings for a number of people over the year, organising people to attend and venues, and so on, created barriers to maintaining a focus on each person.

There were also examples where planning was crisis driven, and therefore carried out under strict time constraints that limited person-focus and authenticity.

It was very clear that quality planning was more effective in organisations that were able to embrace a person-centred culture and focus.

The culture of a service, incorporating its underlying values and principles, is a major influence on the way in which services are designed, planned, and delivered (Emerson & Stancliffe, 2004; Mansell & Beadle-Brown, 2004; Marrone, Hoff, & Helm, 1997; Routledge & Gitsham, 2004). Organisational culture "steers the development of relationships between users and providers and is often evident in the way that frontline staff interact with users. A service culture that embraces ideas of empowerment and inclusion, is open to possibilities, willing to take risks and think outside traditional planning models, is therefore likely to facilitate person-centred planning." (Dowling, Manthorpe & Cowley, 2007, p. 79)

Theme 2: Listening and giving credence to what a person with a disability says

BACKGROUND

It has long been evident that commonly, the voices of people with a disability have not been heard or acknowledged in areas that directly affect their lives. In settings of custodial and institutional care, people with a disability were generally assumed to be incapable of having contributions to make and it was up to those in positions of authority to work out and deliver what was considered best. We can now recognise the very low expectations concerning people with disabilities that underpinned this approach, and developments since the 1960's have reflected increasingly higher expectations for both people with a disability and services.

There have been many developments over the past two to three decades that have led to a greater range of higher quality opportunities in all aspects of life, and greater means to have a say, for people with disabilities. The ideas and techniques of person-centred planning have emerged alongside developments such as community living, inclusive education, and open employment. Various forms of advocacy have been crucial.

However, many barriers remain. Service developments since the custodial era have been accompanied by increasing levels of professionalism and complexity, such that the voices of people with disabilities can often be lost in the system. In planning efforts across the disability field, many people continue to struggle with the challenge of truly listening and responding to the voice of individual people with a disability.

KEY ISSUES

1.   Participation by the person

There were examples during the Project where people for whom planning occurred did not participate in the planning in any way, including actual attendance at meetings where they were the subject of planning. There is a significant risk in these situations of reinforcing to the person and to significant others that the person is not important, does not deserve the respect of being included, and has little to contribute to shaping their own future.

In contrast to this, there were examples where the person was completely involved in all elements of the process, with whatever support was required to make it happen. Those involved in the planning process were genuinely interested in the person and they spoke with respect to, and about, the person. One family member spoke about an increase in trust because of this demonstration of respect and interest in their family member. This contributed to a better relationship (which had been very fractured and tenuous in the past), and to positive outcomes for those involved.

In one case study in which there was a clear person-centred approach, there was a genuine commitment to, and focus on, the individuals that the service supported. This was confirmed in interviews with senior staff, support workers, family members, and with the individual with a disability. The planning processes in this situation were not standardized or set in the context of an organizational requirement. They were relatively informal, ongoing, and specifically tailored around what the individual wanted and needed.

2.   <u>Listening</u>

Listening to people requires giving attention to the person's whole range of communication methods including verbal, (speech, noises, vocalisations), body language, behaviour, mood, and facial expressions. The people involved in the person's life, including the service provider, can listen from the perspective of the person, considering why something is important for the person even if it doesn't make sense for others. This involves listening in a way that assists the person to find their voice and to develop their sense of self and their place in the world (O'Brien & O'Brien, 1995; Smull, 2000; Pitonyak, 2002).

O'Brien and O'Brien (1995) referred to listening as:

> "…thoughtful investigation of a person's biography, discerning expressions of competence, interest, concern, and passion in the person's responses to day-to-day experience, creating invitations for considered discussions, acknowledging vulnerabilities, fears, disappointments, taking an active interest in taking the person's point of view and seeing how their actions make sense to them, even when they seem discordant or opaque to others". (p. 16)

It was evident through the interviews that some service providers found this to be challenging, especially when requests or wishes of the person appeared to be unrealistic, when options appeared to be unavailable, when it involved/created risk for the person, or when there was a conflict of views between the person and their family/representative.

3.   Listening to people with limited communication

Many planning efforts happen for, and on behalf of, people who have very limited ability to communicate. Indeed, a great deal of planning concerns people who have no power of speech and limited alternative means of communication that are easy to discern. Finding a way to communicate with some people is a challenge which may result in not involving the person in the planning. Forest and Pearpoint (1998, p.96) noted that "if people with power choose to plan 'for' people without having them present, then the label on the tool makes no difference".

A communication ally is a person who uses their "fluency privilege" on behalf of people who experience limited or impaired ability to communicate fluently. In planning meetings, their role is to ensure the situation is structured so the person is fully heard, informed, and respected through the process. They seek to counteract both the systematic oppression, and the internalised oppression experienced by people who are not fluent speakers in a particular community (Shevin & Kalina, 1997).

A communication ally/advocate is important for people with a disability to find their voice and to be listened to in a way that reflects their own perspective. It is critical that these allies/advocates have integrity and that guiding beliefs for their advocacy are grounded in respect and the principles of person-centred support.

Theme 3: Respect the natural authority of the person with a disability and the family

BACKGROUND

In the past, individual planning processes have generally been owned and managed by service providers from the viewpoint that professionals know what is best and where the balance of power in the relationship has been with the service provider.

Planning processes need to incorporate productive relationships between paid providers and outside resources and take advantage of including people with disabilities in those processes. Concepts of empowerment, self determination, and the 'right relationship' between service providers and people with and disability and their families are important influences on planning processes (Kendrick, 2003a).

KEY ISSUES

1. <u>Assumption of the natural authority of the person</u>

In Western cultures, the assumption of natural authority residing with the person and then with the family/representative is highly valued. The authority of individuals and family members to speak for themselves and control their own affairs is crucial in order for planning to be culturally appropriate and relevant to those concerned (Browder, Cooper, DaCosta, Lim, Rucker, & Cavaiuolo, 1999; Cook & Abraham, 2007; Kendrick, 1995; Kendrick, Jones, Bezanson, & Petty, 2006).

Planning processes can enable individuals and families to identify their own needs and the strategies required to meet them. Some of the simple strategies encountered in the Project included maintaining regular conversations about the person's needs and implementation or action that matched the person's plans; creating informal environments, such as over coffee around the dining table, to ensure the person and/or family feel comfortable; and developing an attitude that acknowledges the person and/or family as the natural authority in regard to the person's life.

There were also examples where the person's family felt they had to fight and challenge the service provider/s to retain their natural authority and to influence the

planning to achieve good outcomes for their family member. This required determination and commitment.

O'Brien and Mount (2005, p.58) wrote: "the dispersal of authority and accountability for life planning and plan implementation also necessitates deep role change for staff described as mid-level professionals".

2.	Cultural and religious considerations

The goal of being culturally responsive has become more prominent in recent years, and many challenges remain in this area. People with disabilities and their families who have language and cultural differences may be under-represented at planning meetings (Callicott, 2003) and may not share similar expectations about teaching, learning, or parenting (Manning & Lee, 2001). Effective INP will take into account those cultural and religious differences both in the processes used and the outcomes sought.

Trainor (2007) found culturally appropriate person-centered planning approaches had the following characteristics.

- Providing more opportunities for people/families to be involved and to direct the planning. Engaging the person and families was based on the facilitator's knowledge and experience of the culturally-based values and practices in their communities.

- Engaging authentic participation by the person and important others in ways that made sense for them, such as being able to use their first language.

- Providing the opportunity for the organization and facilitation of the planning to be flexible such as using audio recordings or other means to record the planning discussions where the family could not read or write, and locating meetings in homes or other culturally appropriate environments.

- Building the 'right' relationships between people involved.

- Providing a focus on future planning and self determination within the context of their culture.

Blue-Banning, Turnbull, and Pereira (2000) described how the person-centered ethos fitted well with the Hispanic cultural value of developing personal relationships that are predicated on warm, individualized attention and responsiveness in personal interactions.

3.   <u>Development of respectful relationships.</u>

Service providers may be given, or may assume, a position of power in the relationship with people with a disability and their families. It is a barrier to effective planning where power is unevenly balanced in the relationships involved in individual needs planning. All people involved in the planning need to have a respectful relationship with the person with a disability and the necessary values and ethics are demonstrated in the way the person is supported (Kendrick, 2003b).

Kendrick (2000b, 2003a) has written about the need for 'right relationships' between people with a disability and their supports. This entails an atmosphere and approach of mutual respect, sharing of authority, and a commitment to working together.

> "Michael Kennedy, an activist for disability rights who grew up in institutions and uses personal assistance services, identifies power sharing between people with disabilities and their assistants as a process of shared learning. While he wants the responsibility for the final decision when there are disagreements, he does not dictate to his assistants because they have valuable ideas to offer him. Trust and joint responsibility for learning are the keys to teamwork (O'Brien & O'Brien,1996, p.10)."

Theme 4: Continuity of relationship and depth of knowledge of the person

BACKGROUND

For many years, people with disabilities were segregated from society and from their families and friends. Family members were advised to "put them in an institution and move on with your life". They were not encouraged to maintain contact with the person and neither was the person supported or assisted to maintain contact with them.

For most people living in institutions, service staff tended to be the main, or perhaps only, people in the person's life. Staff turnover in some situations has left a person with a disability with no one knowing them well. The person may have very few freely-given relationships and very little contact with people outside the institution.

While the justifications for segregation, for the most part, are no longer overtly supported, social isolation is still a very common experience, especially for people with developmental disabilities. The lack of freely given relationships in the lives of people with disabilities remains a difficult issue for many service providers to tackle. Discontinuity of relationships is a common experience through disconnection from loved ones and high turnover of support staff. This lack of being known and understood by others dramatically affects planning, particularly where a person with a disability is unable to easily communicate their own aspirations.

KEY ISSUES

1. <u>Importance of continuity of close relationships</u>

Having a range of people who have close, long standing personal connections with the person with a disability puts planning on a much more solid footing, and addresses the limitations of staff having to create and implement a plan on their own. The personal knowledge, genuine concern, and variety of resources and ideas that family members, friends, advocates, and long-serving staff can share create a strong foundation for planning efforts to remain focussed on the person with a disability.

The case studies revealed that there were family members and long-term support workers involved in the planning who had deep personal knowledge of the individual. These people knew the individual well and understood the person's history and life.

This was even more important where the person was unable to speak on their own behalf. The case studies also included examples of people with a disability who had very few people with knowledge of their life, needs, or preferences. It was apparent that individual needs planning was more effective for those who had people who knew them well.

2.   <u>Limitations in identifying needs because of limited knowledge of the person</u>

Limited consistent relationships made it more difficult to identify or understand the person's real needs and preferences. This included paid as well as unpaid (freely given) relationships. There were examples where the person with a disability had moved homes a number of times in a short space of time and on each occasion had to develop relationships with new support staff. There were a number of examples where the support staff shortages impacted on the person having consistent support throughout the planning process. In one example, planning occurred when there was no-one who had known the person for more than three months.

These situations demonstrated the challenges that service providers faced and reflected real limitations that are built into the service system.

Theme 5: A focus on quality processes and outcomes rather than tools

BACKGROUND

While individual needs planning has its origins in Lifestyle Planning as developed by John O'Brien in the 1980's, there has since been a proliferation of approaches, many of which remain in use in various forms today. These include MAPS (Vandercook, York, & Forest, 1989), PATH (Forest & Pearpoint, 1998), Essential Lifestyle Planning (Smull, 2000; Sanderson, Kennedy, Ritchie, & Goodwin, 1997), Circles of Support (Snow, 1995), and Personal Futures Planning (Mount, 1989) amongst others. These approaches share a number of characteristics including having a distinctive role for a facilitator, using graphics and pictures, and being embedded within principles that underpin quality planning.

O'Brien et al (1997), Mount (1989) and Kendrick (2003b) have indicated that the risks are great when specific planning techniques are applied in isolation, without due regard for the broader principles of person-centredness and quality service. Risks also exist when planning is done:

- By agencies that are unable to create significant change;

- As a standard process;

- By people who do not know the person well;

- In the absence of crucial and important people in the person's life;

- By overregulated systems where bureaucracy and professionalism dominate.

Individual planning in WA disability accommodation services is typically an annual planning process that follows a standardized format. It is usually developed, managed, and implemented by the service, with the person and other significant people as contributors. Service providers, as evidence of compliance with Disability Service Standards, are required to ensure that each person has an individual plan. The purpose of the individual planning process is to identify individual needs, goals, and lifestyle choices, with the development of an action plan to meet these goals.

Some of the difficulties associated with these processes reflect a concentration on the planning tool. This increases the tendency of planning processes to become

standardised and formalised, limiting both the capacity to tailor processes around individuals and relevance for some key stakeholders.

KEY ISSUES

1.   Over-reliance on standardised planning tools

The case studies suggested that planning processes frequently focused on completion of a lengthy document by the service provider. This was acknowledged to be cumbersome, with the format and questions often unsuitable to the needs of the person with a disability. The surveys indicated that although agencies had a general understanding of why they planned with people, the planning process was overtaken by the need to have formal requirements met through the completion of documentation.

The case study that was considered to provide the best outcomes for the individual and most closely incorporated the principles of person-centredness, used no formal tool or process. Rather the individual needs planning was carried out in a regular, informal way and included key stakeholders in informal environments such as around the person's kitchen table. Neither specific directed questions nor a formal facilitator were used. Importantly, all of the people involved had a strong commitment to person-centeredness. While this informal approach may not work in all situations, it raised questions about considering planning as being much more than the completion of a formal process. It challenged the assumptions driving the current focus on INP tools, including that:

- Planning requires a tool;

- Planning requires a 'planning meeting'

- A product (the plan) should be produced by planning.

2.   Outcome issues

It has been proposed that evidence of services' implementation of person-centered values and approaches should be seen in the quality of people's everyday lives, not solely in written documents (Beadle-Brown, 2006; Kendrick, 2003b; O'Brien & Lovett, 1992; Routledge, Sanderson, & Greig, 2002).

Person-centred planning is at risk of being adopted by agencies as a tool using the words and the jargon, yet compromising on the values, qualities, and components of person-centred approaches. This leads to a reinvention of just another planning approach which makes little change to the life of the person. It can become a system-based document which serves the agency and not the person (Holburn & Vietze, 1999; Kendrick, 2003b; O'Brien & Lovett, 1992; Ritchie, 2002).

> "So, for advocates, change agents, progress minded leaders, innovative service providers and many others who seek a better world, the challenge of authenticity in person-centeredness is ultimately a question of truth and discernment, coupled with an increased willingness to become a great deal more demanding and principled as to what we will settle for. The dangers in unduly trusting in appearances and symbols can only be offset by paying much closer attention to the realities of people's lives, and less to claims of success that are not upheld in practice." (Kendrick, 2007, p. 7).

Holburn and Vietze (1999) noted the difficulty in assessing the success of person centered planning specifically related to achieving outcomes for people. A systematic literature review carried out some years ago (Rudkin & Rowe, 1999) established that there was no empirical evidence to support a connection between person-centred planning and any specific outcomes for people with disabilities. It has only been in very recent years that some empirical evidence has started to emerge, with outcomes attributable to person-centred planning and implementation having been reported in areas including engagement in activities, contact with family and friends, and choice (Robertson et al, 2006).

Positive outcomes have been attributed to a number of factors including staff values; skills in, and understanding of, person-centred support, the person and their allies; and energy and commitment to creating outcomes. Poor outcomes have been associated with high case loads; lack of advocacy training; and constraints of resources, time, and transport (Dowling, Manthorpe, & Cowley, 2007; Mansell & Beadle Brown, 2004; Rasheed, Fore, & Miller 2006; Rhodes & Hamilton, 2006).

Planning can be a paper-based exercise, with plans written with the right, person-focused language and inspirational goals, but may not be matched by the actions taken. Plans may sit in a file and not drive service strategies and responses.

The following factors have been found to be related to successful outcomes for people in residential services who had a person centered plan (Robertson et al, 2006).

- Personal involvement of the individual. People owning and directing the planning in ways that they wanted.

- A person-centred team, with leadership, stability of staff, and evidence of the prior existence of person-centred approaches.

- A facilitator who had planning as part of their formal job role.

- The facilitator's commitment to person-centred planning. This was the most powerful predictor of successful outcomes

- Managers actively involved in planning.

- Where the facilitators were first line managers, with some responsibility for the planning.

Theme 6: Identifying real needs

BACKGROUND

From its beginnings with John O'Brien's five accomplishments, INP processes have addressed fundamental human needs – needs for affiliation and relationships, being in and part of the community, and having valued social roles and competencies. At the same time, people may have pressing needs that require urgent attention. The "real" needs of an individual may incorporate both fundamental and pressing needs and effective INP requires processes to identify what these needs are. These processes incorporate participation and exploration by people who know the person with a disability well and, by their nature, are deeper than a checklist or formulaic approach.

KEY ISSUES

1.   <u>Not addressing social isolation and loneliness</u>

"To be vulnerable is not to be in jeopardy. To be vulnerable and isolated is the matrix of disaster" (Gaylin, 1990).

Many people who experience formal services are lonely and much of their suffering results from isolation, not disability. Often, people with a disability are provided with programs and interventions when their desperate need is relationships (Pitonyak, 2002). The ultimate value of a service system may come from its success in helping people to maintain and develop positive and enduring relationships (O'Brien, 1984).

Romer (2002, p.1) posed the following questions when planning with people.

- Are enough people engaged in the person's life?

- Are there people who are imbued with the belief and hope for a brighter, better future for the person?

- If not, how might such people be found or how might that sense of hope be instilled in those committed to walking with the person?

Research shows that a person who has many social contacts – a spouse, a close-knit family, a network of friends, church, or other group affiliations – lived longer and

had better health. People who were socially isolated had poorer health and died earlier. In fact, those who had few ties with other people died at rates two to five times higher than those with good social ties (Hafren, Karren, Franden, & Smith, 1996).

Some people encountered in the case studies had no relationships with people who were not paid and yet planning did not acknowledge and address this issue.

2.   Appreciation of the person and their history

Understanding someone takes time. Understanding someone who has multiple and complex support needs usually takes longer. People with multiple or complex support needs are best supported in intimate settings by people who know them well.

Appreciating a person's history also includes understanding a person's heritage and culture. Each person who participated in the interviews obviously had their own life history, challenges, and triumphs. It was important to note that their particular history, as with all of us, greatly impacted and shaped the people they are today, how they and their families engage with service providers, among many other things.

A young woman's life included moving out of home as a child into a hostel, then moving to a smaller group living arrangement, then moving into her own rented unit with staff engaged to support her. This process continued to be labeled as challenging due to behaviours that had developed over many years which limited her lifestyle, friendships, and her choices of employment and recreation. The behaviours were magnified by her inability to cope with even small changes in her environment or routines. Good planning with this woman was evident, and included enabling her to direct her own life, taking small steps, building trust with her and her family, and taking calculated risks which ultimately achieved positive outcomes for her.

3.   Discerning high order needs and low order needs

One of the key indicators of effective INP was the ability to identify and respond to a person's real and critical needs.

Individual needs planning provided better outcomes when it was bottom up (person driven) as opposed to top down (service driven). The contrast between these methodologies is reflected in two questions.

"What do you want and how can we or others support you to get it?

"What have we got to offer you within our current service strategies and how might this match what you want?

Theme 7: A developmental process, underpinned by high expectations

BACKGROUND

People with a disability historically have been labelled and stereotyped in ways that are negative and reflect very low expectations. Raising expectations continues to be a challenge for disability services and a great deal of values-based training seeks to address this goal. From the earliest developments in person-centred planning, high expectations for positive change have been embedded in approaches to planning and implementation.

KEY ISSUES

1.   Capacity vs deficiency view

People with a disability and their skills, capacities, and contributions have often been hidden due to negative labeling and stereotyping. Quality planning seeks to discover the person's capacities, skills, and contributions both in their home and their community life, and then discovering people, places, and activities that value that contribution. It also starts from the assumption that the service system should not be the automatic provider of all support to the person (O'Brien, O'Brien, Mount, & Rosen, 2001; O'Brien & Mount, 1989).

Raymond Kilroy (as cited in O'Brien and Mount 1989), a vigorous advocate for himself and other people with a disability, gave testimony to the US Senate about his vision for himself and all people with a disability. His vision draws attention to new directions.

> "We are moving away from emphasizing my needs toward building upon my capacities. We are moving away from providing services to me in some facility toward building bridges with me to communities and neighborhood associations. We are moving away from programming me and other people with disabilities toward empowering us and our families to acquire the support we want. We are moving away from focusing on my deficits to focusing on my competence. We are moving away from specialized disability organizations so that we can develop and sustain

relationships with people who will depend upon people like me and upon whom people like me can depend." (p. 6)

The opposite of a capacity view is a deficiency view, where it is assumed that people cannot do things, cannot contribute, cannot communicate, cannot engage, and cannot succeed because of the limitations of their disability.

2.   High and realistic expectations

The case studies showed that INP was more effective (as described by individuals, families and staff) when it was underpinned by high expectations about the person (i.e., expecting the person to be able to achieve and focusing on the person's strengths and capacities as well as needs). Someone with the person's best interest at heart challenged low expectations. It is important to note that while expectations were seen as high for an individual, they were also seen as realistic and achievable.

It is interesting to note that what was once considered unrealistic for people with a disability is now considered to be a right. This includes being able to direct and contribute across all areas of life, living in one's own home, living in the community, have meaningful friendships and relationships, and meaningful and engaging work, to name a few.

Realistic and high expectations were demonstrated in a case study with a young woman who had an intellectual disability and a physical disability. She utilised a wheelchair, hoist, and other equipment that enabled her to be mobile in her home and in the community. It was anticipated that her mobility would continue to deteriorate and she would become more dependent on support staff and was at risk of moving from her individualized support arrangement into group living. Planning from a capacity view challenged those predictions and actually resulted in the woman gaining increased mobility to the point where she was no longer in need of a hoist for transferring and could utilize a regular car for transportation instead of a van. This impacted significantly and positively on her independence and engagement within her home and community.

3.   Limited life experience

Limited life experience can provide a real challenge in planning efforts. People who have lived in institutional settings, for example, will often have had very limited real world experience in that time. It is also the case that some people with disabilities have little experience in key areas of life such as work roles and friendships. It is therefore to be expected that many people will have a limited store of experience and knowledge upon which to draw in conversations about their preferences and wishes in such areas.

This can be reflected in the sameness of written plans. Staff may be reluctant to impose their own ideas about new experiences that may benefit a person with a disability. However, the ideas of staff and anyone in an important relationship with the person with a disability can be crucial in providing a broader foundation of experiences from which the person can more clearly form and express their own ideas and future goals.

4.   Differing expectations

Effective INP may need to respond constructively to situations in which there are differing expectations between the person with a disability, the service provider, family members, and others close to the person. This is a test of how well the planning process leads to agreement on a way forward that closely reflects the needs and wishes of the person.

5.   Limitations of group living

Block funding was managed by the service provider and allocated according to the support needs of groups of people. This was a 'top down' approach that strongly limited the possibilities for flexible, individualized support arrangements as an option. The emergence of individualized funding and arrangements by which individuals and families can govern this have created important new opportunities for person-centred approaches to flourish. The legacy of top down planning and implementation based on the needs of groups remains a common situation in residential support services and presents challenges not easily overcome.

Throughout the Project, it was evident that people with a disability who were supported in group living arrangements were accorded significantly less natural authority in their home than those people who were supported in a more individualized and person-centred manner. Group arrangements meant significant compromises were necessary because of the competing needs of the other people with whom the home was shared. This contributed to workload issues with support staff needing to spread their time and energy across a number of people with limited capacity to focus on one person at a time

Theme 8: Safeguards

BACKGROUND

There is increasing emphasis in the disability field on risk management procedures to help reduce the vulnerability of a person with a disability and to respond to any adverse event experienced by the person with a disability, the support staff, and the agency.

Safeguards seek to address the inherent vulnerabilities associated with having a disability. Kendrick (2002a) wrote about the need for intentional safeguards. Intentional safeguards refer to those measures introduced to strengthen and renew existing safeguards and to create new ones in order to protect something of value. For example, a person's stake in their home may serve to protect it. Building and supporting important relationships in a person's life is a fundamental safeguard against isolation and poor treatment.

KEY ISSUES

1.   Relationships

What matters most to people's safety is the extent and quality of their relationships. People are safer the more others care enough about their safety and well-being to keep a close eye on their situation, to stand up to difficult situations with them, to act imaginatively in response to their vulnerabilities, to negotiate on their behalf with others who control important opportunities, and to struggle with them over situations in which they are contributing to their own problems. Many people with a developmental disability are more vulnerable exactly because they lack opportunities and assistance to make and keep good relationships (O'Brien, 1993).

An important safeguard evident in some of the case studies was having several people involved in the planning who knew the person well, including people within the service in direct care and management roles. This increased the likelihood that the person's goals and plans were honoured and that the person's goals were not unduly influenced by just one person. Participants were able to keep each other accountable for implementation over the longer term.

2. <u>Dignity of risk</u>

Dignity of risk refers to a commitment to each person's right to control his or her life, including both good and bad experiences. There is much debate about the dignity of risk within the disability sector. Service providers are often uncertain about their responsibility to keep a person safe from harm versus the developmental benefits from risk-taking. Duty of care may place limits on risk-taking because of legal responsibilities.

Robert Perske (1972) wrote about how overprotection can keep people from becoming all that they could become. Many of our best achievements come the hard way: "We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try".

It was apparent in some case studies that effective planning processes were considering risks in a balanced way, taking into account the person's choices, history, decision making ability and experiences, as well as necessary safeguarding options.

Kendrick (2002b) wrote about the need to:

- Cultivate a greater appreciation of the vulnerabilities that may be present.

- Develop a sense of priority and hierarchy of needs and vulnerability.

- Identify the values and principles that ought to guide the making of safeguarding decisions.

- Identify who has the authority to make safeguarding decisions.

- Identify and strengthen existing safeguards as may be helpful.

- Identify areas of vulnerability where insufficient safeguards currently exist.

- Target safeguards on a person-by-person basis.

- Recognise the potential developmental and remedial dimensions of safeguarding in addition to solely preventive safeguards.

Theme 9: Leadership

Leadership is a necessary ingredient of principled and effective change. The history of reform in the disability field is no different to other areas of social change. INP had its leaders and champions at many levels, including from families and people with a disability. Leaders have been prepared to challenge the status quo, to develop ideas that inspired, and to act on those ideas in order to enhance the lives of people with a disability.

While individual needs may be identified, effective strategies to support people to achieve their goals may be missing. This could be compounded if there is a lack of people responsible and committed to the person to lead planning and its implementation (Kendrick, Jones, Bezanson, & Petty, 2006).

Theme 10: Flexible approaches

BACKGROUND

Effective INP requires a high degree of flexibility and a willingness to think laterally and innovatively. Although service systems are by nature formalized and rule-governed, in recent years more flexible approaches to funding and delivering services have been developing.

KEY ISSUES

1.   Agency approach and strategies

Authorities in the area of person-centred planning assert that for people with disabilities to have the life that they want, virtually all existing human service policies and agencies must attend to:

- The way they regard the people they serve;

- How they support those people;

- Their relationship to communities;

- The way they spend money;

- The way they define staff roles and responsibilities; and,

- The way they exercise authority (Cook & Abraham, 2007; Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Rasheed, Fore, & Miller 2006; Routledge, Sanderson, & Greig, 2002).

O'Brien et al (1997) and Mount (1989) stated that when agencies are in a position of leading person-centred planning, they need to be mindful to build in flexibility and responsiveness, actively involve and empower all people who are important to the individual, and avoid unnecessary bureaucracy and professionalism.

In the case studies for the Project, a flexible approach to individual needs planning tended to be associated with better outcomes experienced by people.

Characteristics of a flexible approach included:

- Family/significant others who know the person well were involved, and were able to lead the planning in the way that made sense for the person;

- Planning was timely in response to changing needs;

- The INP process used was tailored to the real needs of the person and goals were adapted as the person's experiences and preferences changed;

- The most flexible methods utilised were those that built the planning around the person.

2.   Individualised funding

Individualised funding has developed in recent years and provides important opportunities for services to become more person-focused and to shift some authority and power from the service provider to the person. Individualised funding is consistent with the world-wide trend toward increased rights, self-determination, and community involvement for people with a disability. Direct individualised funding of disability supports is viewed as one important element for contributing to the possibility that people have genuine options and control in their lives.

STRATEGIES

Numerous strategies associated with good individual planning and implementation emerged from the review of literature and from consultation with stakeholders in the case studies and the surveys. Many of these have been presented as part of the description of themes in the preceding section. This section provides a summary of strategies to achieve effective individual needs planning in the context of accommodation support services.

Element 1: Intention – Reason for the planning

Theme 1: A person centred organisational culture	
Issue	**Strategy**
1.1 Service-focused or person-focused organisational cultures?	Evaluate and develop the organisation's culture. Develop and maintain a genuine person-centred culture. This requires consistent commitment and reflection from an organisation's leadership. It requires investment and resources to ensure individuals are committed to people. It requires that a person-centred commitment is reflected in the organisation's values and mission. It is even more important that it is consistently reflected in the organisation's actions particularly over time. For example in the regard given to people who use the service, the language and tone used to speak to and about people, and the people selected to work within the organisation.
	Invest in training, knowledge, and expertise in person-centred principles and values for all stakeholders.
	The organisation should undertake critical and independent evaluation of the effectiveness of their person centredness and approach to services. This allows for an organisation to have some opportunity to continue to develop, respond, and change in order to meet the person's needs.
	Organisations need to honestly evaluate and recognise the incongruencies between their philosophy and their practices.

Element 2: Effectively identifying needs and aspiration

Theme 2: Listening and giving credence to what a person with a disability says	
Issues	**Strategy**
2.1 Participation of the person. It is fundamental to high quality INP that the person for whom the planning is carried out is actually engaged in the planning.	Develop INP in a way that allows the person to fully participate. Consider what makes the person comfortable and structure INP in a way that includes the person.
2.2 Listening to the person. It is not enough that the person just participates - they need to be listened to. For some people this may also mean listening to others who may genuinely speak on their behalf	Ensure that people involved in the planning do listen to the person. Those who are in leadership roles should model this behaviour and attitude. Listen to the person and what is important to them, over the whole year – not just when a planning meeting is scheduled.
2.3 Listening to people with limited communication. Many planning efforts happen for, and on behalf of, people with very limited ability to communicate. Where a person has limited communication, it is important to find ways for the person to communicate.	Use a communication ally – a person who uses their "fluency privilege" on behalf of people who experience limited or impaired ability to communicate fluently. In the planning process their role is to ensure the situation is structured so the person is fully heard, informed, and respected. Investigate and use communication methods that can support people to have a voice including utilising assistive technology

Theme 3: Respect the natural authority of the person with a disability and the family	
Issues	**Strategy**
3.1 Assumption of natural authority of the person. The stakeholders involved in the INP respect the authority of individuals and family members to speak for themselves and control their own affairs.	Enable people with a disability to direct planning in a way that makes sense for them. Find ways to keep family and friends engaged in the person's life. Maintain regular conversations about the person's needs and implementation or action that matches the person's plans. Create informal environments, such as over coffee around the dining table, to ensure the person and/or family feel comfortable. Develop and encourage an attitude that acknowledges the person and/or families as the natural authority in regard to the person's life. The person and people important to him/her are included in the planning and have the opportunity to exercise control and make informed decisions
3.2 Cultural and religious considerations. Effective INP will take into account cultural and religious differences both in the processes used and the outcomes sought.	Engage authentic culturally appropriate participation by the person and important others.
3.3 Development of respectful relationships.	Develop an atmosphere and approach of mutual respect, sharing of authority, and a commitment to working together between all stakeholders.

Theme 4: Continuity of relationship and depth of knowledge of the person	
Issues	**Strategy**
4.1 Importance of continuity of close relationships. INP is more effective with the involvement of people who know the person well.	Invest in establishing, developing, and maintaining relationships in a person's life. Develop relationships with family and other important people in the person's life.
4.2 Limitations in identifying needs because of limited knowledge of the person	Spend time getting to know a person before engaging in the planning process. Include diverse groups of people, invited by the person, to assist in planning and decision making Recognize that inviting people to work together in a constructive manner toward a positive vision is one of the most important responsibilities of planning

Theme 5: A focus on quality processes and outcomes rather than tools	
Issues	**Strategy**
5.1 Over-reliance on standardised planning tools.	Allow planning to happen in a way that is natural and meaningful for the person. Focus less on a standard tool and more on what will work for the person.
5.2 Does planning result in outcomes for people?	Ensure that ongoing consideration is given to actions to address needs and aspirations that are identified during the INP processes. The person's dreams, interests, preferences, strengths, and capacities are explicitly acknowledged and drive activities, services, and support. The person achieves personal goals.

Theme 6: Identifying real needs.	
Issues	**Strategy**
6.1 Not addressing social isolation and loneliness.	Facilitate organisational awareness of the importance of natural and community supports to individuals.
	Genuinely appreciate the person's history and life experiences.
	Continue to seek people to invite into the person's life in a way that makes sense for the person, such as local community members, family, friends, and advocates.
	The person develops and uses, when possible, natural and community supports and generic resources.
	The person has the opportunity to be a contributing member of the community.
	Challenge expectations and old beliefs that 'nobody would want this person'.
6.2 Appreciation of the person and their history.	Take the time to understanding a person's history, life experiences, heritage, and culture.
	Understand that behaviour challenges may be a means of communication.
6.3 Discerning high order needs and low order needs.	Listen carefully to those who know the person well.
	Spend time with the person and their family to understand who they are.
	Don't rush through the INP.
	Consider the person's situation from a number of angles including health and well being, engagement, and purpose.
	Consider what is important 'for' the person versus what is important 'to' the person
	Don't be tempted to address only the needs and aspirations that are easy.
	Be willing to struggle with higher order needs such as need to belong and need for purpose and place in the world.

Element 3: Developing appropriate strategies to respond to needs

Theme 7: A developmental process, underpinned by high expectations	
Issues	**Strategy**
7.1 Capacity versus deficiency view. Acknowledging a person's strengths and contribution.	Ensure stakeholders engaged in INP focus on discovering a person's strengths and capacity, as well as needs Discover where in the community those capacities and interests are shared and welcomed.
7.2 High and realistic expectations.	Ensure stakeholders engaged in INP have high and realistic expectations for the person. Ensure at least one person involved in the INP is willing to challenge low expectations. Challenge expectations and aim high.
7.3 Impact of limited life experience on a person's aspirations.	Encourage people to have ongoing access to a range of experiences. Where appropriate, encourage input from others who know the person well.
7.4 Differing expectations. Respond constructively to situations in which there are differing expectations between the person with a disability, the service provider, family members, and others close to the person.	Ensure the planning process leads to agreement on a way forward that closely reflects the needs and wishes of the person
7.5 Limitations of group living. Competing needs in congregate settings provide particular challenges for effective INP.	Ask the question 'is this how the person wants to live their life?' Are there other options for this person? What needs to happen to get it for them? Priority should be given as much as possible to the needs and aspirations of each person with high consciousness to minimize the limitations of congregate settings. Where people with a disability live in group settings, find ways to reinforce their authority and control over their home. Seek participation in community life and citizenship activities rather than automatically choosing human service setting solutions.

Theme 8: Safeguards – intentionally responding to likely risks and individual vulnerabilities.	
Issues	**Strategy**
8.1 Relationships	Try to include several people in the planning who know the person well, including people within the service in direct care and management roles. This increases the likelihood that the person's goals and plans will be honoured and that the person's goals are not unduly influenced by just one person. Participants keep each other accountable for implementation over the longer term. Acknowledge, respect, understand, and respond to personal vulnerabilities
8.2 Dignity of risk - opportunity to experience measured risk	Intentionally respond to likely risks and individual vulnerabilities. Identify a person responsible for reviewing both risk and opportunity.

Element 4: Action - Implementing the identified strategies from the INP and reviewing the person's situation

Theme 9: Leadership	
Issue	**Strategy**
9.1 Leaders have been prepared to challenge the status quo, to develop ideas that inspire, and to act on those ideas in order to enhance the lives of people with a disability.	Foster leadership within key stakeholders. Ensure INP process has committed person/s to lead and see the process through. Critically evaluate if what the person wanted to happen actually happened?

Theme 10: Flexible approaches - a willingness to think laterally and innovatively.	
Issues	**Strategy**
10.1 Agency approach and strategies to build flexibility and responsiveness in INP.	Actively involve and empower all people who are important to the individual, and avoid unnecessary bureaucracy and professionalism.
	Allow planning to be carried out in a way that makes sense for the person.
	Ensure planning is timely in response to changing needs.
	Address barriers concerning the person's image and reputation at home and in the community.
	Organizations invest in developing new community opportunities, creating the opportunity for people to develop new connections and roles, and supporting people's contribution.
	Provide occasions for people in the organisation to deepen their understanding of the ethical issues at stake in providing services to people who are socially devalued.
10.2 Individualised funding - one important element for contributing to the possibility that people have genuine options and control in their lives.	Explore possibilities to provide resources including funding as individually and flexibly as possible.

CONCLUSION

This project set out to explore the key issues concerning the implementation of best practice in individual planning around the needs of people with developmental disabilities.

While empirical evidence for person-centred planning is only beginning to emerge, its values and practices have long been associated with service qualities and characteristics that stakeholders hold to be desirable. The balance of information gathered in this project supports the assertion that attention to planning and implementation that is person-centred pays off in terms of enhanced service quality and better outcomes for individual people with disabilities.

A major conclusion from the project is that organisational culture is absolutely vital to the achievement of effective individual needs planning and outcomes. Essentially, this is a values-laden process. If the organisational values are not strongly person-centred, then effective INP is very difficult if not impossible to achieve.

Organisational culture must incorporate ongoing commitment to these values and acknowledgement of the need to continually address their renewal. The values, principles, and practices that drive service provision together with a clear understanding of why planning is important, and how that fits with the role and responsibility of the agency is the foundation of quality planning.

The model of accommodation support impacted substantially on the effectiveness of individual planning. Those people who were supported in an individualised way were provided with more flexible, creative planning processes which led to more opportunities that were coherent with the person's culture, needs, and preferences. It was apparent that when people were living with other people in shared support (group homes and hostels), the issue of competing needs of the group limited service providers' ability to identify and respond to individual wants and needs. In addition, limitations flowed from situations where people with a disability were moved from one location to another, primarily to address system needs.

Better planning was associated with a general commitment to quality service, based on a close personal knowledge of, and commitment to, each person. High expectations, the active involvement of all relevant people (including the individual,

family and friends), a long term outlook, and implementation expertise were also crucial factors.

Individual Needs Planning - Detailed Survey

Individual Needs Planning Project

The Individual Needs Planning Project is a joint project between Nulsen Haven Association, NDS (WA) and Curtin University. The project aims to identify and widely disseminate the evidence base for best practice in planning around individual needs of people with disabilities in accommodation services. The project is funded by the Disability Services Commission under the 2007 Quality Systems Improvements Grant.

Individual Needs Planning may include person centred planning, personal futures planning, essential lifestyle planning or less structured strategies to determine a person's needs.

Survey

This survey is part of the Individual Needs Planning Project and seeks your perceptions of the effectiveness of Individual Planning in your organisation. The survey is in WORD format. Please type your responses into this WORD file, save the changes and return via email by 30 December to:

Leanne Parsons

L.Parsons@curtin.edu.au

The survey has six sections and will take approximately 30 – 45 minutes to complete.

Section 1: Demographics

Name:

Role of respondent:

Organisation:

Number of individuals to whom your agency provides accommodation support:

Section 2: Understanding Individual Needs Planning

2.1   Please describe why you or your agency currently plans around individuals.

2.2   What do you see as the principles underpinning good quality planning around individual people with disabilities?

Section 3: How do you plan around individuals?

3.1   Within the agency, who organises individual needs planning and what is their role?

3.2   Please list the people both within and outside your agency who are typically directly involved in individual needs planning and describe their roles.

3.3   How extensively do you engage in individual needs planning in your agency? What proportion and how many of the people do you support have individual needs plans?

3.4   How are decisions made about which people you support, have access to individual needs planning?

3.4   Please describe a typical individual needs planning process within your agency.

3.5   Please provide any additional information that describes how your agency plans around individuals.

Section 4: Outcomes of planning

4.1   What outcomes for the agency are achieved as a result of individual needs planning?

4.2   What outcomes for individuals are achieved as a result of individual needs planning?

4.3   How do you determine if these outcomes are achieved?

Section 5: Effectiveness of planning

5.1   How effective is the current planning process in achieving outcomes for individuals? (*Does the service or support change as a result of planning? Does planning change people's lives for the better?*)

5.2   What works well with your current planning?

5.3   What do you find difficult with the current planning?

5.4   What factors in the current planning lead to the person achieving good outcomes?

5.5   What factors in the current planning process are barriers to the person achieving good outcomes?

Section 6: Improvements

6.1   What could be done differently to improve planning around individuals in your organisation?

Section 7: Further involvement in the Individual Needs Planning Project

If asked, can you suggest someone who has been through your individual needs planning, who might be willing to participate in a personal interview for the purposes of the project? This may involve a person with a disability, family member/s of the person with a disability, direct support staff etc.

Confidentiality will be strictly maintained. The information that is provided in the interviews will be used to inform people about the Project outcomes, however, no information will be provided in a way that identifies individuals or agencies.

REFERENCES

Beadle-Brown, J. (2006). Person-centred approaches and quality of life. *Tizard Learning Disability Review*, 11 (3), 4-12.

Beadle-Brown, J., & Mansell, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services*. Journal of Applied Research in Intellectual Disabilities*, 17 (1), 1-9.

Blue-Banning, M., Turnbull, A.P., & Pereira, L. (2000). Group action planning as a support strategy for Hispanic families: Parent and professional perspectives. *Mental Retardation*, 38, 262-275.

Browder, D., Cooper, K., Da Costa, J., Lim, L., Rucker, R., & Cavaiuolo, D. (1999). An evaluation of variables that influence the selection of participants for innovative services. *Journal of Developmental and Physical Disabilities*, 11 (1), 47-59.

Callicott, K. (2003). "Culturally Sensitive Collaboration within Person-Centered Planning." *Focus on Autism and Other Developmental Disablties*, 18 (1), 60-68.

Cook, T., & L. Abraham (2007). An evaluation of the introduction of facilitated person centred planning with people with learning disabilities leaving a hospital setting: sharing the knowledge. *Tizard Learning Disability Review*, 12 (4), 11-20.

Dowling, S.,Manthorpe, J., & Cowley S (2007). Working on person-centred planning: From amber to green light? *Journal of Intellectual Disabilities,* 11, 65-82

Education for All Handicapped Children Act of 1975, 20 U.S.C. Public Law 94–142.

Emerson, E., & Stancliffe, R. J. (2004). Planning and action: Comments on Mansell and Beadle-Brown. *Journal of Applied Research in Intellectual Disabilities,* 17(1), 23-26.

Finkelstein, V. French, S., Swain, J., & Oliver, M. (Eds) (1993). *Disabling barriers - enabling environments*. London: Sage in association with the Open University.

Forest, M., & Pearpoint, J. (1998). The Ethics of MAPS and PATH. In J. O'Brien & C. L. O'Brien, (Eds) *A little book about person centred planning* (pp. 93-103). Toronto: Inclusion Press.

Gaylin, W. (1990). *On being and becoming human.* New York: Penguin Books.

Hafren, B.Q., Karren, K.J., Frandsen, K.J., & Smith, N.K. (1996). *Mind/body health: The effects of attitudes, emotions, and relationships*. Boston: Allyn and Bacon.

Holburn, S., Jacobson, J., Schwartz, R. A., Flory, M. J., & Vietze, P. M. (2004). The Willowbrook Futures Project: A longitudinal analysis of person centred planning. *American Journal on Mental Retardation,* 109(1), 63-76.

Holburn, S., & Vietze, P. (1999) Acknowledging barriers in adopting person centred planning". *American Journal on Mental Retardation,* 37 (2),117-124.

Kendrick, M. J. (1995). The natural authority of families. *Crucial Times*, Brisbane, Australia. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick, M. J. (2000a). *When People Matter More Than Systems. The promise of opportunity*. Albany, NY. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick, M. J. (2000b*). Right relationship. Queensland Advocacy Incorporated Newsletter*, Part A and B, March 2000 and July 2000. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick, M. J. (2002a). Values, authenticity and integrity. *Values: Cost or investment*. Wellington, New Zealand. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick, M. J. (2002b) Intentional Safeguards for Older People. *Conference Proceedings: Values: Cost or Investment*, NZ Council of Christian Social Services pp. 18-22. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick, M. J. (2003a). The role of personal integrity in upholding 'right relationship' in organisations, *CRUcial Times*, 28, 4-5. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick, M. J. (2003b). Some predictable cautions concerning the overemphasis and over reliance on person centred planning. *The Frontline of Learning Disability*, 58.. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick M. J. (2007). The challenges of authentically getting what people actually need on a person-by-person basis*, T*he Frontline of Learning Disability*, I69, Dublin, Ireland. Retrieved 30 September 2008 from http://www.kendrickconsulting.org.

Kendrick, M. J., Jones, D. L., Bezanson, L., & Petty, R.E. (2006). *Key components of systems change. First of three papers on unlocking the code of effective systems change.* Retrieved 30 September 2008 rom http://www.kendrickconsulting.org

Manning, M.L.,& Lee, G.L. (2001). Working with parents – Cultural and Linguistic considerations. *Kappa Delta Pi Record*,37 (4),160 -163.

Mansell, J., & Beadle-Brown, J. (2004a). Person-centred panning or person-centred action? A response to the commentaries. *Journal of Applied Research in Intellectual Disabilities,* 17(1), 31-35.

Mansell, J., & Beadle-Brown, J. (2004b). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities,* 17(1), 1-9.

Marrone, J, Hoff, D., & Hlem, D (1997). Person-centred planning for the millennium: We're old enough to remember when PCP was just a drug. *Journal of Vocational Rehabilitation,* 8 (1), 285-297.

Mount, B. (1989). Making futures happen: A manual for facilitators of personal futures planning. St Paul, MN: Governers Council on Developmental Disabilities.

Mount, B. (1992). More than a meeting: Benefits and limitations of personal futures planning. In J. O'Brien, & C. L. O'Brien (Eds) *A little book about person centred planning.* Toronto: Inclusion Press, pp. 55-68.

Nirje, B. (1969). The normalization principle and its human management implications. In R. Kugel, & W. Wolfensberger (Eds), *Changing patterns in residential services for the mentally retarded.* Washington, DC: President's Committee on Mental Retardation, pp. 179-195.

Nirje, B. (1980). The normalization principle. In R. J. Flynn, & K. R. Nitsch, *Normalisation, social integration, and community services.* Baltimore, MD: University Park Press, pp. 31-49.

O'Brien, C. L., & O'Brien, J. (2000). *The origins of person-centred planning. A community of practice perspective.* Lithonia, GA: Responsive Systems Associates, Retrieved 30 September 2008 from http://thechp.syr.edu/rsapub.htm.

O'Brien, J. (1984) A guide to personal futures planning. Lithonia, GA: Responsive Systems Associates.

O'Brien, J. (1993) *Supported living: What's the difference?* Lithonia, GA: Responsive Systems Associates, Retrieved 30 September 2008 from http://thechp.syr.edu/rsapub.htm.

O'Brien, J., & O'Brien, C.L. (1995). Learning to listen. In J. O'Brien. & C. L. O'Brien (Eds) *A little book about person centred planning.* Toronto: Inclusion Press. pp. 15-18.

O'Brien, J., & O'Brien, C.L. (1998). *The politics of person-centred planning.* , Lithonia, GA: Responsive Systems Associates. Retrieved 30 September 2008 from http://thechp.syr.edu/rsapub.htm.

O'Brien, J., O'Brien, C.L., & Mount, B. (1997). Person-centred planning Has arrived...or has it? Mental Retardation, 35(6), 480-484.

O'Brien, J., O'Brien, C. L., Mount, B., & Rosen, F. (2001). Pathfinders. Making a way back from segregation to community life. Retrieved 30 September 2008 from http://thechp.syr.edu/rsapub.htm.

O'Brien, J., & Lovett, H. (1992). *Finding a way toward everyday lives: The contribution of person centred planning.* Retrieved 30 September 2008 from http://thechp.syr.edu/rsapub.htm.

O'Brien, J., & Mount, B. (1989). *Telling new stories. The search for capacity among people with severe handicaps.* Lithonia, GA: Responsive Systems Associates. Retrieved 30 September 2008 from http://thechp.syr.edu/rsapub.htm.

O'Brien, J., & Mount, B. (2005) *Make a difference: A guidebook for person-centered direct support.* Toronto: Inclusion Press.

O'Brien, J. & O'Brien, C. L. (1996). *A tune beyond us, yet ourselves - power sharing between people with substantial disabilities and their assistants.* Retrieved 30 September 2008 from http://thechp.syr.edu/rsapub.htm.

Perske, R. (1972). The dignity of risk. In W. Wolfensberger (Ed.) *Normalization: The principle of normalization in human services.* Toronto: National Institute on Mental Retardation, pp. 194-200.

Pitonyak, D. (2002). Opening the door. In J. O'Brien, & C. L. O'Brien, *Implementing person-centred planning: Voices of experience.* Toronto: Inclusion Press, pp. 99-120.

Ritchie, P. (2002) A turn for the better. In J. O'Brien & C. L. O'Brien, *Implementing person-centred planning: Voices of experience.* Toronto: Inclusion Press, pp. 11-24.

Rasheed, S. A., Fore, C., & Miller, S., (2006). Person-centred planning: practices, promises and provisos. *The Journal for Vocational Special Needs Education*, 28 (3) 47-59.

Rhodes, J., & Hamilton, D. (2006). An Insight into implementing person-centred active support. *Tizard Learning Disability Review*; 11, 3, 37-42.

Robertson, J., Emerson, E., Romeo, R., Knapp, M., McIntosh, B., Sanderson, H., et al. (2006). Longitudinal analysis of the impact and cost of person-centred planning for people with intellectual disabilities in England . *American Journal on Mental Retardation*, 111(6), 400-416.

Romer, M. (2002). Two is not enough. In J. O'Brien, & C. L. O'Brien, *Implementing person-centred planning: Voices of experience.* Toronto: Inclusion Press, pp121-129.

Routledge, M, & Gitsham, N. (2004). Putting person-centered planning in its proper place. *Tizard Learning Disability Review*, 9 (3),21-27.

Routledge, M., Sanderson, H., & Greig, R. (2002) Planning with people. In J. O'Brien, & C. L. O'Brien. *Implementing person-centred planning: Voices of experience.* Toronto: Inclusion Press, pp. 373-396.

Rudkin, A., & Rowe, D. (1999) A systematic review of the evidence base for lifestyle planning in adults with learning disabilities: Implications for other disabled populations. *Journal of Clinical Rehabilitation* 13(5), 363-372.

Sanderson, H., & McIntosh, B. (2006). Value Added. *Community Care* Retrieved on 30th September 2008 at http://www.communitycare.co.uk/Articles/2006/04/20/53651/value-added.html.

Sanderson, H, Kennedy, J, Ritchie, P., & Goodwin, G. (1997). People plans and possibilities: Exploring person centred planning. Edinburgh: SHS Ltd.

Shevin, M., & Kalina, N. (1997). On being a communication ally. Presentation at the annual conference of TASH, Boston, December 1997.

Smull, M., & Burke-Harrison, S. (1992). *Supporting people with severe reputations in the community.* Virginia: National Association of State Mental Retardation Programme Directors.

Smull, M. (2000). Selected writings by Michael W. Smull on essential lifestyle planning, self-determination, and organizational change. Retrieved on 30 September 2008 from http://au.wrs.yahoo.com/_ylt=A0oGk21118BJ.WYAgm0L5gt.;_ylu=X3oDMTByZWgw N285BHNlYwNzcgRwb3MDMQRjb2xvA3NrMQR2dGlkAw-- /SIG=12cmupdf5/EXP=1237461237/**http%3a//learningcommunity.us/documents/lis tenlearnact.pdf.

Snow, J. (1995). Participation through support circles. In J. O'Brien & C O. O'Brien (Eds) *A little book about person centred planning.* Toronto: Inclusion Press, pp. 83-87.

Trainor, A. (2007). Person-centred planning in two culturally distinct communities: Responding to divergent needs and preferences. *Career Development for Exceptional Individuals*, 30(2), 92-103.

UPIAS. (1976) *Fundamental principles of disability*. London: Union of Physically Impaired Against Segregation. Retrieved 30 September 2008 from http://www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/fundamental%20principles.pdf.

Vandercook, T., York, J., & Forest, M. (1989). The McGill action planning system (MAPS): A strategy for building the vision. *Journal of the Association for Persons with Severe Handicaps*, 14, 205-215.

Wolfensberger, W. (1972). Normalization: The principle of normalization. Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1983) Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, 21(6), 234-238.