



LIVING LIFE MY WAY

**Putting people with a disability
at the centre of decision making**

Summit report

August 2011

Acer Arena

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Executive summary

The Hon. Andrew Constance MP, NSW Minister for Disability Services, hosted a two-day Summit on 7 and 8 July 2011 to bring people together to explore person centred approaches to disability services and supports in NSW. The theme of the Summit was *Living Life My Way*.

A person centred approach

A person centred system places the person with a disability at the centre of decision making when it comes to the supports and services they use.

In a person centred system the rights of people with a disability, and their families and carers, to direct their lives are respected. A person with a disability and their families and carers are heard and supported to exercise choice and to direct supports and service arrangements.

Summit content

Over two days almost 500 Summit participants considered the meaning and importance of person centred ways of working and the outcomes sought. Panel discussions focused on hearing directly from people with a disability, their families and carers, service providers and the sector about their experiences of working in a person centred way. Workshop discussions focused on the following themes:

- 1 Person centred planning, flexibility, choice and control
- 2 Personalised funding arrangements
- 3 Personalised service delivery
- 4 Outcomes from a person centred approach for people with a disability, their families and for the service sector.

Summit findings

There was a general consensus amongst Summit participants that a person centred approach is a positive direction to take.

The things that people said were important and mattered the most to them included:

- having a real say in planning services and supports, including flexibility to tailor supports to personal needs, choose supports and clarity around the roles of different people in the planning process
- having their views respected
- the option to control a personal budget and access support and guidance in budget management
- the ability to access services and supports in flexible ways that suited their lifestyles
- support for service providers to implement the changes required to achieve a person centred system.

These are seen as essential attributes of a person centred system.

The outcomes sought by Summit participants related to greater personal freedom, empowerment and happiness which are enabled by choice and control over the supports and services they use in their daily lives.

The individual outcomes from a person centred system were expressed as:

- I have a life full of possibilities
- I achieve my potential
- I live the life I want to live
- I have control and freedom of choice
- I am respected and treated with dignity
- I am a valued member of the community
- I have the resources I need to lead a happy and healthy life.

Next steps

The Summit was an important first step in a much broader, statewide consultation process, which will occur over the next 12 months. We will be seeking the views and ideas of people with a disability, their families and carers and the sector, through focus discussions all over NSW.

The outcomes of the consultations will be used to develop an approach to implementing a person centred system in NSW. The approach will be tested in a second round of consultations during 2012 before being put into place.

1 Introduction

In the last 20 years there has been a major shift in attitudes to recognise the rights of people with a disability. *The United Nations Convention on the Rights of Persons with Disabilities 2007*, which Australia signed in 2008, recognises the rights of people with a disability to determine their own lives and participate in communities to the fullest extent possible.

Internationally and within Australia, governments recognise the implications for disability planning, funding and service delivery. In Australia, the *National Disability Reform Agenda and Strategy* commits all jurisdictions to work together to build a sustainable and person centred disability support system.

The Productivity Commission's inquiry into a National Disability Insurance Scheme is exploring ways to overhaul the current system. It aims to provide certainty around funding, increase access to services and supports and make services and supports more person centred.

In NSW, people with a disability and their families and carers have expressed the need for greater choice and control over supports and services they access in their daily lives. They have provided personal accounts of how inflexible supports and services impact their ability to lead the lives they want.

1.1 What is a person centred system?

A person centred system places the person with a disability at the centre of decision-making for supports and services they use.

In a person centred system the rights of people with a disability and their families and carers to direct their lives are respected. A person with a disability and their families and carers are supported to exercise choice and direct their supports and service arrangements.

There are three core aspects of a person centred system:

- 1 Person centred planning: planning that is personalised and directed by the person, where possible, with support if needed
- 2 Personalised funding: resources are allocated to provide supports based on the person's needs, which are identified through the planning process
- 3 Personalised service delivery: delivery involving a combination of formal and informal, public and privately provided services, which are coordinated to deliver the best outcomes for an individual.

1.2 The Summit – *Living Life My Way*

The Hon. Andrew Constance MP, NSW Minister for Disability Services, hosted a Summit on 7 and 8 July 2011 on person centred approaches for people with a disability. It brought together people with a disability, their families and carers and service providers to talk about what a person centred approach would look like and the outcomes people would like to see. The theme of the Summit was *Living Life My Way*.

The Summit was held at Acer Arena in Homebush, Sydney and was attended by 474 people. Fifteen per cent of participants were people with a disability, seventeen per cent were family members of people with a disability, ten per cent were the carers of people with a disability, forty per cent were service providers and the remainder were government personnel and other stakeholders. The Summit was facilitated by a team from KPMG.

The Summit included panel discussions with people with a disability, their families and carers as well as service providers. These discussions explored people's experiences with person centred approaches in NSW and other states and the benefits and outcomes achieved. There were also a number of opportunities for smaller group discussions around four areas of focus:

- 1 Person centred planning, flexibility, choice and control
- 2 Personalised funding arrangements
- 3 Personalised service delivery
- 4 Outcomes from a person centred approach for people with a disability, their families and carers, and for the service sector.

1.3 This report

This report provides a summary of discussions from the Summit and identifies the main themes and issues identified during the group discussion sessions and panel discussions. This report covers the four main focus areas of the Summit.

2 Person centred planning, flexibility, choice and control

2.1 Introduction

Participants spent time in discussion groups considering how person centred planning processes need to be designed to ensure they deliver flexibility, choice and control in the way people with a disability and their families and carers are supported.

Participants considered:

- the meaning and importance of person centred planning
- what should be included in a person centred plan
- who should be part of the planning process
- the supports that may need to be provided to assist the person with a disability, families and carers and service providers to undertake the planning process.

The main themes from these discussions are outlined below.

2.2 What is person centred planning?

“A person centred plan is very important to me – to know what we are doing for planning and thinking and to ensure there is something in place for the future. It reduces stress for me and provides clarity. It addresses individual needs and looks to the person first.”

Workshop participant

Person centred planning was consistently identified by Summit participants as an essential tool for providing greater choice, flexibility and control. Many discussion groups agreed that person centred planning has the potential to change the conversation between individuals and service providers, to explore what is possible and not just what is already available. Many recognised value in the planning process not just producing the document itself. The planning process provides the basis for talking about a person’s future, aspirations and support needs.

Strong personal ownership of the plan by the person with a disability was identified as essential to effective planning. Many participants also emphasised the need for service providers to recognise the importance of the plan and respect it as a reflection of the person’s aspirations and needs.

A small number of participants were concerned about the potential consequences of requiring all individuals to have a plan in order to access supports. The focus on producing a wide-ranging ‘life plan’ was seen as an imposition on some

people with a disability who do not need supported planning to get on with their lives. Participants proposed that in these cases a plan should be limited to the provision of supports and funding. A simplified planning process and document could be used as the basis for determining supports and funding and for monitoring expenditure.

“A plan has to be meaningful and the focus must be on achieving quality of life. A plan for the sake of a plan is not useful.”

Workshop participant

Most discussion groups emphasised that a person centred plan should not be in a standardised format. Instead it should be tailored to reflect the needs of the person concerned. Many recognised that planning should be:

- based on the idea that the goals and aspirations of the person with a disability and their family and carers are at the centre of the service system
- wide ranging and driven by the life the person wants to live, their dreams and the full range of life possibilities
- focused on the person’s life course and identify supports for their current and future life stages
- strengths-based and focused on the supports the person requires to lead the life they want and maximise their confidence, happiness and social inclusion
- dynamic and reflect the person’s changing circumstances and choices over time, to allow for new experiences to be tried and tested.

As one panel member noted that by focusing on individual strengths, dreams and aspirations a person centred system can change the assumptions that many people have about what it is like to live a life with a disability.

2.3 Content of the plan

Generally there was a view that the plan should cover the goals and aspirations of the person with a disability as well as their family and carers. The main points raised about the content of the plan were:

- The plan needs to be flexible and reflect a person’s short and long-term goals.
- The plan should be holistic and include factors the person identifies as important – including health and personal supports, accommodation, leisure and employment.
- The plan needs to provide clarity about available resources and funding for supports and activities.

There was general agreement that the planning process must consider supports beyond the funded disability service system and include informal networks, the general community and mainstream / universal services.

Some participants saw the planning process as a way to identify the person with a disability's support requirements, particularly where supports are needed to achieve goals and aspirations. This may result in some challenging conversations amongst family members. Such conversations may be related to the independence of a person with a disability or their long term needs, particularly for circumstances when a person's family and carers have passed away.

Other participants spoke of the need to acknowledge the responsibilities, as well as the rights, of people with a disability within the context of their informal care networks and community.

Participants recognised the importance of the plan to focus on actions and supports and timeframes for achieving them. However, participants also commented that while the plan needs timeframes it must be adaptable over time, evolving as a child grows into adolescence and adulthood, with the person's wishes given greater authority as they age. As a result, planning may need to undergo a subtle shift from 'family centred' for a child to 'person centred' as they become an adult.

Many participants identified a need for success measures to be in the plan to assess its implementation. Some groups spoke of the need for flags or triggers for review. For example, when there are issues at key transition points in the person's life or where their circumstances change.

2.4 Who should be included in the planning process?

There were differing views about who should be involved in the planning process:

- Most discussion groups agreed that planning should include the person with a disability and anyone they chose to involve. This could include their immediate and extended family, their circle of friends, carers, advocates, medical professionals (for example, general practitioners, psychiatrists and other specialists) as well as mentors and other significant people in the person's life.
- Some groups also identified the need for other trusted professionals to participate, such as an independent planner / facilitator and legal and financial advisers. Not all of these people may need to be involved in the same planning meeting, but they could be engaged through the process.

“The planning process should include anyone who is important to the person with a disability and who they choose to be involved.”

Workshop participant

- Some participants believed that service providers and support workers should be involved in the planning process provided they are flexible and consider options for the person with a disability beyond services they directly provide. Other groups argued that planning should be separated from service providers and the services the person currently receives.

All participants wanted the process to be person centred and controlled by the person with a disability. Some acknowledged that family involvement in planning can be a sensitive issue and needs to be separately discussed with the person at the start of the planning process.

Participants recognised that the planning process needs to be culturally appropriate, particularly for Aboriginal people and people from culturally and linguistically diverse (CALD) backgrounds. This may require people from the person's broader family, kinship, religious and community networks being involved in the planning.

One panel member spoke of the importance of community involvement when planning with Aboriginal people with a disability and of the need to strengthen their community to be able to provide support.

Case study: Importance of involving the community

The community can play a vital role in a person centred approach, providing community support for people with a disability, opportunities for community engagement and participation and connection to networks.

As expressed by one participant, this is particularly important for Aboriginal communities, which experience higher rates of disability than the broader population but may not have the same understanding of the language or concept of disability.

A person centred system can bring a culturally appropriate approach to service provision in Aboriginal communities, acknowledging that formal services are not always the best response and that building capacity in the community can be more effective. It can also help recognise and value skills already existing in communities and uses a strengths-based approach so that formal services better meet the needs of people with a disability.

2.5 Planners

Most participants recognised a role for someone, of the person with a disability's choosing, to coordinate and facilitate the planning process.

Some of the identified roles for a planner include:

- ensuring the person with a disability is the focus and has the strongest voice in the process
- acting as an advocate for the person to assist them to have a voice
- knowing the person and their needs and aspirations
- providing advice about the rules and guidelines around the assessment, planning and funding arrangements
- providing information and organising supports
- assisting with and organising communication aides and supports.

One panel member spoke of their family's experiences and challenges in being the planners of their son's life under a person centred system.

Case study: Planning by the family

A person centred system can change family dynamics, as experienced by one mother and carer of a son with a disability.

Under the person centred system, the family was no longer the primary driver of support for their son, which they found challenging.

However, the dialogue established as part of the new approach has fostered a new closeness within the family and their son is now part of the "vision-making" of their life. Not only has this empowered their son but it has taken pressure off family members from needing to guess his needs, dreams and goals. It has also lead to other family members having a closer relationship with him.

Generally, participants agreed that a planner should be someone who is trusted to represent the person with a disability. Some believed they should be skilled at facilitating and should stand alongside the person, rather than leading the process.

"I need an honest broker to assist me in the planning process."

Workshop participant

There were mixed views about who the planner should be, their role and whether they should be independent from a person's service provider. There is a risk that when the planning process is directed by a service provider, it will be based on which supports are readily available. However, others recognised that in some circumstances service providers may be appropriate for the role.

2.6 Support to participate in planning

A common theme was the need for information and support to inform the planning process. It was acknowledged that some, but not all, people with a disability may require information and support to participate in the planning process. Some areas that were identified where support may be required include:

- training and support so that the process is effective for people with a disability, families and carers and service providers
- access to information to inform choices – people with a disability need to know what supports are available and how to access them, as well as examples of peers who have achieved similar goals
- a single point of contact
- an independent facilitator
- a budget with sufficient resources and accountability
- service providers who are willing to take on board, and adapt to, the person's needs
- assistance with budgeting
- communication aides to assist people with a disability to express their needs and aspirations and control the process
- emotional support for parents, families and carers to work through difficult issues and 'let go' of the person with a disability
- culturally appropriate support that is consistent with the values, language and culture of the person and their family.

3 Personalised funding arrangements

3.1 Introduction

This discussion session provided an opportunity to consider personalised funding and its role within a person centred system, in particular:

- support that may be needed to assist people with a disability and their families and carers to manage their own funding
- circumstances where personalised funding arrangements may not work and the identification of possible alternatives
- factors that should determine access to a personalised funding package.

The main themes from these discussions are outlined below.

3.2 Choice of funding arrangements

Across the discussion groups there was consistent support for the implementation of personalised funding arrangements to enable people with a disability, their families and carers to exercise greater choice about the supports and services they receive.

There was a consistent view that personalised funding arrangements should be flexible, allowing the person with a disability to choose how funds are managed. Options included:

- direct payments to people with a disability who are willing and able to determine how the funds would be spent and manage the funds independently
- payment of the personalised funding allocation to families or carers who would manage it on behalf of the person with a disability and in accordance with their choices
- payment to a third party to manage the funds on behalf of the person with a disability. Third parties could include formal financial managers, guardians or the Public Trustee, brokerage services, or nominated service providers.

“People with a disability need to have options – from being self managed to being managed by a service with personal control and choice.”

Workshop participant

In line with the theme of choice and flexibility, many participants noted there should be flexibility to change arrangements for managing personalised funds if the needs or capacity of the person with a disability, their families and carers change.

Case study: Making mistakes is part of the process

Self-management under a person centred system can instil self-confidence and empowerment for people with a disability.

For one person, the previous system was inflexible (the support provided did not fit into her schedule). It was also unresponsive to her needs. For example, she was given a male care worker despite being uncomfortable with this.

Now, self-management is a way of life and she feels more in control of her life and destiny. She has taken on roles in the community and feels like she has something valuable to contribute. Importantly, self-management means she can do things spontaneously like her able-bodied peers.

The process has not been without its challenges and a key part of the journey for her has been to try new things and not be afraid to make mistakes. The biggest challenge under a self-managed model for her was recruiting her own workers. Good agency facilitation has been important in ensuring she can communicate her needs and obtain the right services.

3.3 Support to manage funding arrangements

Participants suggested that some people with a disability may not initially have the skills required to manage their own funds but with time and support could develop those skills and be able to take a greater role in managing their funds.

It was also noted that many families and carers may not want to take on the additional responsibility for managing funds. Some expressed the view that this would be another “burden” for families and carers, particularly having to account for the expenditure.

Some specific questions that arose in relation to options for the management of funds included:

- will the person with a disability own the funds, regardless of who manages them?
- will the funding allocation be treated as income for taxation purposes and will it affect eligibility for access to other services?
- will families or carers be required to obtain Power of Attorney or other legal status in order to manage funds on behalf of the person with a disability?
- what will happen if the person with a disability and their family or carer have a different view about how the funds should be spent?

Participants also expressed some concern about the management of personalised funds. This includes the potential for funds to be mismanaged or spent in ways that do not meet the person with a disability’s needs for supports and services.

While this concern was raised in a number of groups, it was generally agreed that with the right supports and safeguards, this risk should be low and not be a barrier to change. Some groups suggested a voucher system as an alternative to direct payments. Other participants cautioned against making the system too prescriptive and rule-bound in reaction to the small risk of misspending.

A number of groups also described the need for the Government to recognise that some people will make mistakes in managing their funding allocation. It was suggested that the Government should adopt a continuous improvement or learning approach rather than punishing individuals.

A number of different supports were suggested, including:

- information that is appropriate for people with varying communication requirements
- financial advisers – it was suggested that these should be independent and act solely in the interest of the person with a disability
- budgeting and money management training
- culturally appropriate resources for people from Aboriginal and CALD backgrounds.

Additionally, participants identified the importance of access to alternative funds management mechanisms, such as brokers or other third parties. In these cases, participants described the need for appropriate checks to ensure the interests of the person with a disability are protected and that there should be clear guidelines about the role and accountabilities of third parties.

3.4 How should funding be allocated?

Generally, participants agreed that personalised funding should be available to all people with a disability who want it. There was general agreement that funding levels need to be determined in a transparent, fair and consistent way.

However, there was a range of views about how decisions regarding funding levels should be made. A key issue for many groups was the need to be clear about who is eligible. There was also concern that expanding the eligibility criteria could put additional pressure on available resources and limit the amount available to each person.

“Funding should be linked to the personal plan, not based on a diagnosis – it should be equitable and evidence based.”

Workshop participant

A number of groups indicated that funding allocation should result from a consistent assessment process but there were divergent views about how this should be designed. This included whether the assessment should:

- focus on the level of disability and need
- focus on supports required to enable community participation
- be more flexible and consider what the person with a disability's goals are and how they can be achieved.

There was general agreement that there should be scope for funding levels to change as needs change. This includes allowing funding to change quickly in response to changing needs or circumstances.

Another issue that emerged in many groups was the need to allow unspent funds to roll over to the following year. Participants who supported this view noted that this would allow for planning and saving for more expensive items, such as equipment.

3.5 What services and supports can be purchased?

There was a range of views about what supports should be able to be purchased. Participants indicated that people with a disability, their families and carers should have choice and flexibility. This could include purchasing supports and services from people or organisations other than disability service providers, including mainstream or community based services. One panel member highlighted the benefits of being able to directly employ the support people she needed and liked.

Many participants agreed that clear guidance about how funds can be used is needed. They also noted that this guidance should balance clarity and flexibility.

Participants also suggested that information about what supports and services are available will be important to inform choice. Suggestions for how this could occur included providing access to a database, website or a telephone helpline.

3.6 Pricing services and supports

Participants discussed the need to ensure that supports and services are available at a fair price. Currently, the price of specialist disability services is set through contracts between the Government and service providers. There was some concern about the potential for support costs to rise under personalised funding arrangements. However, participants' views were mixed about whether there is a need for price setting or benchmarking to ensure fair prices.

Feedback revealed that many participants thought that fair prices for quality services are dependent on competition. It was recognised that this competition may not exist initially, particularly in rural areas or where services are highly specialised.

Participants also stated that the price of services in rural areas may also be higher because of the additional cost associated with delivering services in rural areas. For example, costs associated with travel and with transportation.

It was felt that funding arrangements would need to take these situations into account.

“The difference between metro and rural areas needs to be recognised when thinking about the costs of services.”

Workshop participant

3.7 Making the funding system work

Most groups agreed that personalised funding will work as long as the necessary supports and checks and balances are in place.

Clarity and simplicity in the funding model were seen as key to its success.

This includes:

- clear communication of information in ways that people with a disability can understand
- clear guidance about eligibility for funds, access and allocations
- ensuring that funding is flexible and responsive to people with a disability's changing needs, circumstances and goals
- ensuring that people with a disability, their families and carers have real choice about how their funding is managed and by whom
- ensuring that there are not too many rules associated with the funding and that it is not over-regulated.

Additionally, a number of groups identified the need for access to a transparent appeals mechanism so that they can seek a review of decisions about funding allocations.

4 Personalised service delivery

4.1 Introduction

Summit participants spent time exploring the meaning of person centred service delivery and considering the practical steps necessary to change the system. Participants considered the following areas:

- the meaning of personalised service delivery
- the most important steps for service providers to take to change their service models
- the assistance that the service sector requires to make these changes.

The main themes from these discussions are outlined below.

4.2 What is person centred service delivery?

Discussion groups shared the view that person centred service delivery is very different from the traditional approach of delivering standard programs. It was recognised that service providers have been tied to programs and contractual arrangements which specify the types of supports that can be offered.

Participants expressed the view that, despite good intentions, this approach provides very little opportunity for people with a disability, their families and carers to control and direct the way their supports are provided.

Participants spoke about the impact of service constraints on a person's happiness and the difference a more person centred approach can make to daily life. For example, a person being able to choose their own personal carer made a huge difference.

Participants explored the need for Government and service providers to 'flip their thinking' so that services were responsive to the needs and preferences of the person rather than expecting the person to fit in to the service.

Participants agreed that it is vital that service providers are prepared to listen and respect the views of the person with a disability in shaping what service is provided, when, where and by whom.

"In a person centred world, there is respect for the capacity of persons with a disability to direct and shape the services and supports they use."

Workshop participant

4.3 Cultural change

Most discussion groups emphasised the importance of, and need for, cultural change. This is because attitudes and values impact on person centred behaviour. Many people spoke of the need for government and service providers to have a greater focus on the needs and aspirations of the person with a disability, rather than simply the need to deliver a service. This was seen as a fundamental cultural shift necessary to support a person centred system.

Summit participants identified trust, respect, integrity and having an open mind as the key cultural attributes that make a service provider person centred. There is a strong view that government, service providers, families, carers and people with a disability may all need to change the way they think.

“Person centred service providers are caring and respectful with a positive attitude, an open mind and a friendly face.”

Workshop participant

Willingness to listen was regarded as the most fundamental requirement for a service provider to be person centred. Participants and panel members agreed that a person centred service requires listening, above all else.

“It’s not that hard...you just need to sit down with the person and listen.... you figure the rest out together...”

Workshop participant

Some participants flagged that the way that conversations occur between service providers, people with a disability, their families and carers and others needs to be examined. These conversations need to be culturally appropriate and respectful. The listening culture should apply to everyone involved.

People shared personal stories of how the preferences of a person with a disability may be at odds with family members and how respectful dialogue could help to resolve these differences.

Most groups recognised that cultural change would not be automatic and it depends on enablers and drivers such as:

- champions to drive and demand change
- committed leadership to embed person centred thinking within an organisation
- person centred policies and practice guides to drive and sustain organisational change
- recruitment and retention of person centred staff and support workers
- information and knowledge sharing
- openness to sharing experiences and learning from mistakes.

Case study: Services changing to a person centred approach

“Getting the Life You Want” was a project initiated by a Victorian day program provider, under Victoria’s Changing Days Initiative. The project aimed to apply the concepts of self-direction and choice to people with a disability who had higher support needs and older persons. They started with the question “What does directing your own life and being part of decision-making mean to you?”. Strategies were developed in response to need.

A key to the approach was the recognition that people with a disability can’t make real choices unless they can communicate what they want. The provider developed strategies to ensure that each participant had a level of functional communication. This has been empowering and has increased their ability to make informed choices and communicate those choices to people around them.

As well as developing communication tools, the service also:

- provided training for staff
- provided training for parents to support increased decision-making and self-direction by participants
- provided participants with a communication partner and a community partner.

The concept of ‘partners’ has empowered participants and it is this commitment that makes the initiative work.

The service’s community partners are responsible for working with participants to create opportunities for them to participate in a range of activities of their choice in the community. They provide support to the participant and also to the community organisation through information and training.

4.4 Flexible and personalised services

In a person centred system, the mix of services and supports responds to the person with a disability’s needs, circumstances and preferences. Participants agreed that the best way to start is to open up the possibilities. It is important to be creative about the mix of services and supports to achieve a person with a disability’s life goals.

This includes formal and informal supports, familial and other relationships and connections, public and privately provided services and broader community networks. Collectively, these add up to a rich and diverse mix of supports and opportunities that can be tailored to a person’s needs and circumstances.

Access to mainstream services and supports was identified as a significant resource that could be utilised in conjunction with specialist disability services. Participants also saw opportunities within the community and gave personal accounts of using their own advocacy and networks to create employment opportunities or make connections with community groups.

Participants then turned to defining flexible services and supports. In a person centred system services respond to individuals. That means that services and supports may need to be able to be accessed in a range of different locations, at different times of day, inside and outside of routine business hours. Most discussion groups recognised the difficulties in translating that vision into reality. In particular, the demands on the workforce, including government, service providers and individual support workers, were a focus of discussion.

4.5 Choice

Discussion groups talked about the need for, and the importance of, choice. This relates to choice of service or support, choice of provider and choice of when, where and how support is accessed.

“I want to choose who comes into my home.”

Workshop participant

Choice implies that a diverse range of support and service options exist and are accessible. This is not always the case and there were discussions about the role of personalised funding in driving innovation and new service offerings. The general view was that personalised funding could stimulate new service offerings as people use their purchasing power.

Participants recognised that personalised funding could translate into wider use of private supports and services as well as disability services. For example, a person with a disability may choose to spend some their funding on mainstream leisure activities rather than attending a day program.

Information is critical. People with a disability, family members and carers need to know what services are available and which services represent value for money. Government and service providers were seen as crucial to providing a flow of reliable and credible information about services. Some also recognised the potential for informal exchange of information amongst service users, for example, through web-based feedback mechanisms.

Groups discussed the ways that the service sector would need to operate to support personal choice, including:

- the need for some services to be available 24 hours a day, seven days a week
- the need for services to offer a choice of support staff
- the need for services to meet consumer expectations
- the potential for market forces (through personalised funding and purchaser power) to stimulate and diversify the support and service options that are offered
- the challenges associated with supporting personal choice and freedom while still providing quality assurance.

4.6 Involvement in service design

Most participants recognised the need for people with a disability, families and carers to be empowered to shape and influence the way the services work for them. Most groups also talked about the need for service providers to 'let go'.

Suggestions for providing people with a disability, families and carers with greater control over the design of supports and services included:

- service operators proactively introducing direct client feedback mechanisms to inform their service offerings
- government setting up a web based rating scheme that could be used by people with a disability, families and carers to share information about their experience of a service
- greater accountability and transparency about services, how they are designed, the evidence base to support the design and the outcomes intended to be achieved.

4.7 Workforce issues

Workforce was the subject of a great deal of discussion. Participants recognised that flexible service hours and practices depended upon a flexible workforce and that the disability support sector would need assistance, resources, tools and incentives to get there. There are significant resource implications for government and service providers.

The need to attract, recruit and retain people in the disability workforce who have a strong commitment to social justice was raised, along with the need to employ people with a disability.

Changes will be required in the way people work. New skills, new approaches to job design and new accountabilities will be required to achieve person centred service delivery. Staff need to be allowed to innovate and be given permission to try new things and make mistakes. Training is an essential lever for change.

4.8 Support for services to change

A common theme in discussions was that change is not automatic and that the disability support sector needs assistance, resources, tools and incentives to support the change process. Participants identified a variety of areas where support may be required including:

- organisational leadership
- incentives for change, including financial assistance, practical guidance and tools to become person centred
- information, education and training
- financial management / knowledge and skills to enable services to adjust to personalised funding
- partnerships, networks and support to work cooperatively rather than competitively to enable people with a disability to access the best service not just the one with the greatest reach
- showcasing person centred successes to encourage and inspire other service providers as well as showcasing service providers
- freedom to innovate in partnership with clients, accepting that there may be mistakes along the way.

Significant resources will be invested in developing the capacity of the service system over the next five years as a key element in implementing the second phase of *Stronger Together*. This includes the \$17m Industry Development Fund which is administered by National Disability Services, and has been established to direct investment into systemic initiatives that will support the transition to an integrated, efficient, innovative, robust and responsive service system to achieve quality outcomes for people with a disability and their families in NSW. The Fund will support delivery of the vision and strategies of the sector led NSW Disability Services Sector: Directions for Industry Development report which includes a focus on promoting a consistent understanding of a person-centred approaches among people with a disability, their families as well as service providers.

4.9 Safeguards for quality and accountability

In striving for flexibility and choice there is agreement that we still need safeguards around quality and accountability. This was acknowledged as an extremely sensitive and contentious issue with divergent views about how to balance personal choice with quality assurance and safety.

Participants discussed the need to safeguard the most vulnerable people from abuse and neglect. The scenario raised frequently was one in which a person with a disability receives personalised funding and chooses to pay a family member to provide care or support but does not receive quality support. Where do they go? Who do they complain to? How can it be addressed? Do they receive additional funding? Participants varied widely in their views about how to deal with this and recognised that it needed more consideration.

There were different views about the role of accreditation for support providers and lists of 'approved providers'. On the one hand, accreditation and approved provider lists were seen by some as providing a reassurance that the organisation would provide a quality service. On the other hand, some people thought that requiring support providers to be accredited or to be on a preferred provider list would limit choice. It could limit a person with a disability's ability to choose an organisation from outside the traditional disability sector and their ability to pay a person they trust to provide care or support, including family members.

5 Outcomes from a person centred system

5.1 Introduction

During the second day of the Summit, discussion groups focused on identifying the potential outcomes for a person centred approach – outcomes for people with a disability, for their families and carers and for the service system. The most important outcomes identified by Summit participants are outlined below.

5.2 Outcomes for people with a disability

The most important outcomes for people with a disability from a person centred approach identified by Summit participants were:

- 1 I have a life full of possibilities
- 2 I achieve my potential
- 3 I live the life I want to live
- 4 I have control and freedom of choice
- 5 I am respected and treated with dignity
- 6 I am a valued member of the community
- 7 I have the resources I need to lead a happy and healthy life

One of the overarching outcomes sought for people with a disability is empowerment. Personalised planning, funding arrangements and services were viewed by many participants as empowering people with a disability to maximise their opportunities, talents and abilities and lead the lives that they want to lead.

Person centred approaches can also empower people with a disability to consider options outside the confines of traditional service delivery. The importance of risk taking and trialling approaches was identified as important, with one panel participant saying that “making mistakes is an ordinary part of life”. Choice and control provides the opportunity to trial different things and change your mind without being locked into anything.

Exercising choice and budgeting were identified as empowering processes for people with a disability. Some participants said their experience gave them confidence and that they developed skills in areas that had previously been handled by service providers.

“The person needs to be involved and at the centre from the start. If you as a person don’t own it, it won’t work.”

Workshop participant

5.3 Outcomes for families

The most important outcomes for families were identified by Summit participants as:

- 1 Families enjoy quality relationships
- 2 Families are respected and listened to
- 3 Families are supported
- 4 Families are confident that support will be provided over the life of the person with a disability
- 5 Families make informed choices
- 6 Informal support networks are built around families

Family members and carers present at the Summit expressed their support for personalised planning, funding and services. They identified a range of ways that this move would provide positive outcomes for their day to day family life.

Panel members discussed the shift in family dynamics that a person centred approach can bring. Shifts in responsibility and roles were identified as challenging but ultimately rewarding and positive for the person with a disability and their family.

“We will be able to function like ‘normal’ families with ‘normal’ relationships.”

Workshop participant

One of the panel members spoke of the changes that a person centred system required from him and his wife and the benefits that ensued for the family.

Case study: Focusing on the person's strengths and the supports they need to lead the life they want

A person centred system can challenge people's perceptions and assumptions about people with a disability.

Five years ago, both parents of a son with a disability were afraid for their son to try new things, assuming that his disability required 24 hour care. However, his shift to a person centred approach also required changes from them.

Their son now works part-time as a mechanic and council worker and participates in a walking group. He is able to travel independently between all these places and is currently transitioning to independent accommodation.

A person centred system has delivered benefits not only for their son but also for them as a couple. They have been able to resume a closer relationship and not feel constrained by an inflexible and unresponsive service system.

People with a disability at the Summit shared the view that the opportunity to have a 'normal' relationship with a parent, sibling, child or other family member as opposed to a 'caring arrangement' is important.

Family members and carers identified that a sense of security and certainty should also be key outcomes. This can be important for succession planning when a person with a disability's family and current carers may no longer be able to care.

5.4 Outcomes for the service system

The most important outcomes for the service system identified by participants were:

- 1 Quality services that are person centred
- 2 Services are innovative, flexible and responsive
- 3 Services are supported to achieve change
- 4 Services can attract, retain and train qualified staff
- 5 Services work collaboratively

Participants identified that changes in the service system towards a person centred approach can deliver positive outcomes for people with a disability, their families, carers and the service system.

“Services will have a better understanding of the person’s needs.”

Workshop participant

A person centred approach was seen to be able to free up services from the ‘red-tape’ associated with some government contracts, funding arrangements or programs. Services would be able to become more nimble, innovative, responsive and less crisis driven due to the person centred planning and funding approach.

Case study: A system should encourage, not constrain, innovation by service providers

For one parent of a person with a disability, the current system does not encourage innovation by service providers. Following a debilitating stroke a number of years ago, the person was faced with losing access to their service program under the rules at the time. But their service provider was willing to take innovative steps.

The service provider used original methods to service the needs of the person. For example, the service provider used musical therapy under a strengths-based approach. They provided financial support directly to the family so that the person could continue with these musical therapy sessions. The provider also arranged for the person’s friends to visit them in hospital and at home.

The person with a disability has benefited greatly from this exceptional service experience but this was due to a service provider who was willing to go beyond the rules of the current system.

6 Next steps

The Summit was the first step in developing a person centred approach for people with a disability in NSW. Summit participants supported a move towards a person centred approach and, while all discussion groups identified challenges, there was a strong willingness to find solutions.

The Summit commenced a broader consultation process around person centred approaches. During the next stage of consultation, more than 100 focus groups and workshops will be held around NSW with people with a disability, their families and carers, service providers and other sector representatives. The focus groups and workshops will be held in August and September 2011. A full listing of the dates, locations and times of these consultations is available at www.adhc.nsw.gov.au/pca

The ideas, issues and outcomes identified in these consultations will be used to develop a person centred approach for supporting people with a disability in NSW. The approach will be tested in a second round of consultations during 2012 before being implemented.

If you are not able to attend one of the consultations, you can have your say by making a submission via:

Email pcaconsultations@facsnsw.gov.au

Mail Manager, Person Centred Approaches Team
Ageing, Disability and Home Care
Level 5, 83 Clarence Street
Sydney NSW 2000

Phone Person Centred Approaches Team on 1800 605 489

For your opinion to be included, verbal and written submissions need to be received at the above address or by phone before 30 September 2011.

If you need assistance to make a submission or would like further information about other opportunities to participate in the consultation process, please contact the Person Centred Approaches Team on 1800 605 489.