



LIVING LIFE MY WAY

Putting people with disability at the
centre of decision making

Outcomes of statewide consultations

May – August 2012

LARGE PRINT VERSION

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Minister's foreword

Over the 12 months from July 2011, I led the NSW Government's *Living Life My Way* consultation process to seek feedback from people with disability, their families, carers, and other stakeholders on the best way to implement self directed supports and individualised budgets in NSW.

It is great that so many of you wanted to have your say – more than 4,000 people participated in the consultations, registering support for the Government's commitment to reforming the disability system. Your voices are influencing and informing the development of the new disability support system.

This report provides a summary of what you told us in the final consultation stage undertaken between April and June 2012, documenting your feedback on decision supports, individualised funding arrangements, support coordination, quality assurance and transition support for people with disability, their families, carers and the disability sector.

National momentum for the introduction of a National Disability Insurance Scheme (NDIS) has been building at the same time as the NSW Government has been

consulting about and developing the *Living Life My Way* reforms. On 6 December 2012 the NSW and Australian Governments signed an historic agreement to make the NDIS a reality for people with a disability in NSW. The agreement will see the Australian Government invest \$3.32 billion a year from 2018-19 for the NDIS rollout in NSW with the State contributing \$3.13 billion. 140,000 people across NSW stand to directly benefit from the agreement.

The NSW and Australian Governments have agreed to a first stage launch site in the Hunter local government areas of Newcastle, Lake Macquarie and Maitland. From 2013-14, up to 10,000 people with disability will receive reasonable and necessary support through the NDIS.

While the NDIS is being introduced in the Hunter region, the NSW Government will progressively introduce a complementary approach to supporting people with disability to ensure that everyone – people with disability, service providers and mainstream services – are positioned to move seamlessly to a NDIS.

The NSW Government is committed to ensuring that this approach reflects the key features of the NDIS wherever possible.

Thank you for your contribution to this report through your participation in the *Living Life My Way* consultation process.

Andrew Constance

Minister for Disability Services

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1. Executive summary

The New South Wales (NSW) Government is committed to improving the lives of people with disability, their families and carers. People with disability, their families and carers have expressed the need for greater choice and control over state based disability funding and the supports and services they are able to access in daily life.

In 2011 the NSW Government began an extensive statewide consultation process to seek the views of people with disability, family members, carers and service providers on the design of a person centred system for NSW. The consultations were carried out in three stages. Stages 1 and 2 were an initial exploration of the key elements of a person centred system in order to develop reform options, and Stage 3 tested and refined the options for reform.

In total 354 consultations have been held across metropolitan and regional parts of NSW. This includes targeted consultations with Aboriginal communities, people from culturally and linguistically diverse backgrounds (CALD), people with an intellectual disability and people living in

supported accommodation. In addition, 168 written and verbal submissions have been received and analysed.

This report provides a summary of the key themes, views and suggestions arising during the final stage of consultations. The key themes relate to the things that need to be in place to allow people to make informed choices about support and service options in a person centred system. These include:

- access to a range of information sources about support and service options
- access to decision supports to help people make informed decisions and choices
- simple and practical principles and rules around the use of individualised funding
- a regulatory framework that sets expectations for, and signals the quality of supports and services
- support for service users and the sector itself in order to implement change.

This report should be read in conjunction with the discussion paper released in April 2012. The issues and ideas expressed

in this report relate to the options for reform that were outlined in that paper.

Information obtained as a result of the consultations will inform the development of the approach to implementing self directed support and individualised budgets in NSW.

2. Introduction

In 2011, the NSW Government began a process of engaging people with disability, families, carers and the service sector on the need for reforms in order to create a person centred disability support system (person centred system) in NSW. Person centred approaches are based on providing people with disability choice and control over their supports and services. For the purposes of this report, choice and control is taken to extend across all dimensions of service provision and support – the types of supports and services able to be accessed and purchased, who provides them, and how they are planned, designed, funded and delivered.

The NSW Government commenced a three stage consultation process to seek views and ideas on developing a person centred system in NSW, and how the system should work in practice. Initial consultations, conducted between July to December 2011, focused on the core features, attributes and components of a person centred system from the perspective of people with disability, family members and carers.

Participation included people across NSW with a diverse range of backgrounds and disability types. This stage also included targeted consultations with Aboriginal communities and people

from culturally and linguistically diverse backgrounds. Consultation reports detailing the key themes and issues raised during the consultations were released between December 2011 and April 2012.

On the basis of the feedback received in the 2011 consultations, a discussion paper was developed outlining options for reforms to create a person centred system in NSW. The discussion paper should be read in conjunction with this report.

Discussion papers and outcome reports relating to the Living Life My Way consultations are available online at www.adhc.nsw.gov.au/personcentred

In 2012, a third stage of statewide consultations was undertaken between May and August 2012 to seek feedback from people with disability, families, carers, service providers and other stakeholders on the reform ideas and options outlined in the discussion paper. This report provides a summary of the key themes, views and ideas arising out of the third and final stage of consultations.

What is a person centred system?

A person centred system enables people with disability, their families and carers to choose and control support and service arrangements that suit their needs and lives.

Person centred approaches have been implemented overseas and within Australian jurisdictions to varying extents, all with positive outcomes. The emerging evidence from the places that have introduced person centred approaches is that higher levels of choice and control bring positive outcomes in the health, well being and social participation of people with disability, their families and carers, and that they are cost effective¹.

The vision for a person centred system in NSW is a system in which:

- individuals, families and carers are able to make informed choices to shape and influence support and service arrangements to suit their needs

¹ Ottmann, G, Allen, J and Feldman, P (2009) *Self-directed community aged care for people with complex needs: A literature review*, Deakin University, Melbourne.

- individuals are supported to achieve their full potential, live as independently as possible and participate in the community and the economy
- families and carers are supported to sustain positive and healthy relationships and pursue their own goals
- there is a diverse and sustainable disability support sector that offers and delivers quality, person centred supports and services, in cost effective ways.

From a practical perspective, in order for people to exercise choice and control, there are some essential system components that must be in place. These are:

- Information about support and service options
- Decision supports that help people make choices. These supports allow individuals to become informed consumers. They include access to information, access to professionals who can assist an individual tailor supports and services to their needs, and opportunities and mechanisms for people to share information with, and support, each other
- Clear, consistent and transparent eligibility criteria for assessment to determine who receives Government funded supports and services

- Access to an individualised budget for those assessed as eligible with funding allocated to an individual enabling choice in the purchase of supports and services (either directly or through an intermediary) to meet their disability related support needs
- Options for managing funding and coordinating supports that provide choice over how much control a person assumes. While some people may self manage their funding and coordinate their own supports, others may choose a third party or intermediary to perform these roles
- A sustainable and quality support and service system – the support and service sector must have the capacity to provide good quality, tailored supports and services to meet the needs, goals and outcomes of individuals. Reforms must include strategies for supporting the support and service sector to transition to person centred business models (including adjusting to the introduction of individualised funding) while maintaining quality.

A representation of some of the components of a person centred system is shown in Appendix 1. This illustration was used during the consultations to help people think through how the different parts of the system link and work together.

Developing a person centred system in New South Wales

Person centred approaches are not new and have been implemented in a limited way within the NSW disability service system over the last 10 years. A number of existing programs in NSW offer more flexible individualised approaches, for example: Transition to Work, Community Participation, Life Choices, Active Ageing, Attendant Care, and Family and Childrens Programs. These programs provide people with disability greater choice over support and service arrangements and the use of available funding.

In 2011, the NSW Minister for Disability Services, the Hon. Andrew Constance MP, committed to designing a person centred system in NSW based on feedback from people with disability, families, carers and service providers. The experiences of people involved in the existing person centred pilots and programs are also being used to inform options for whole of system reforms.

Options for person centred reforms to the NSW disability system are being developed in the context of Stronger Together Two, and against a backdrop of significant national

reform. The proposed National Disability Insurance Scheme (NDIS) will have a significant impact on disability service provision in Australia.

Consultations with people with disability, families, carers and service providers in NSW

On 7 and 8 July 2011, the Living Life My Way Summit was held, with over 500 people in attendance. This summit, which was the first stage of the consultation process, launched the Government's intentions for whole of system reform, and a process of statewide consultation to inform the development of reform ideas.

The summit was followed by over 170 consultation sessions held throughout NSW between August and December 2011. In stage two, a total of over 3,000 people participated. The ideas, views and experiences of the people who were consulted in 2011 were used to develop reform options for a person centred system in NSW.

A discussion paper detailing these options was released at a launch event on 24 April 2012, ahead of a third and final stage of statewide consultations with people with disability, families, carers and support and service providers. This discussion

paper set the agenda for the consultations that occurred in 2012.

This final stage of statewide consultations took place between May and August 2012. Consultations explored people's views and opinions on the key reform ideas and directions (described in the discussion paper). These included reforms to information, decision supports and planning, individualised funding and support coordination, quality assurance, and the transition to person centred practice. In total, 130 consultations were held involving over 2,300 participants, including:

- people with disability, families and carers
- people from CALD backgrounds
- families with young children
- people with an intellectual disability
- disability support and service providers
- people living in supported accommodation.

People with disability, families, carers and service providers also had the opportunity to provide feedback through written and verbal submissions. In total, 58 of these were received.

Further consultations will occur to develop specific strategies for supporting Aboriginal people and communities to participate fully in a person centred system.

This report

This report outlines the key findings from the final stage of statewide consultations held between May and August 2012. The report summarises the feedback obtained from the consultation sessions and the analysis of written and verbal submissions. This includes consultations with culturally and linguistically diverse communities.

The report is structured as follows:

- chapter 3 discusses the consultation findings relating to decision support and planning in a person centred system
- chapter 4 identifies stakeholder views on individualised funding, individual budgets and support coordination
- chapter 5 outlines the consultation findings relating to quality in a person centred system.
- chapter 5 outlines the issues in supporting people with disability, families, carers and service providers to transition to a person centred system.

3. Decision Supports

Introduction

A person centred system seeks to place the person with disability, family members and carers in the position of being informed consumers. People are supported to choose, and assume control, over supports and services to meet their individual needs. Decision supports and other resources will be available to support people to make choices. These are critical in a person centred system. In order for people to exercise choice, many will need access to accurate and reliable information as well as guidance, and advice at key points in the system.

The principle of choice applies whether a person with disability is making decisions about supports and services themselves, or making decisions with the assistance of family members, carers, guardians, advocates or other trusted third parties. The focus in situations where a person with disability is not making decisions independently is to ensure that the person is involved and supported to express their goals, views and preferences and that these are reflected in decisions. Some consultation participants identified advocates as an important resource within the system where a person requires

assistance to be heard or there are conflicts of interest and opinions impacting on the exercise of choice.

During the 2011 consultations, people with disability, family and carers consistently identified the importance of being able to access information in a variety of ways, including web based, telephone and face-to-face contact. Building on this feedback, the discussion paper outlined reforms to improve access to information and advice in a person centred system including online access to information and points for face-to-face contact, for example, through local coordinators (the Ability Links NSW program is discussed in more detail in section 2.3) and access to skilled support planners.

For the purpose of the consultations, and in thinking about system redesign, online access to information is considered to be just one aspect of communication. It is a complement to published material and direct (telephone or face-to-face contact) information supports. It is recognised that not everyone uses online resources or has access to a computer.

People seek out and engage with information in different ways and the system needs to account for this diversity. Information needs to be available in a range of formats and media (for example, formats tailored to the communication needs of

people with intellectual or sensory disabilities). During the consultations, people with sensory impairments emphasised that they were often excluded from information sharing and communication because it was not conducted in ways that they could engage with.

Ensuring that information is accessible as well as available is critical. For people from CALD communities the key issue is the accessibility of the information where English is not a person's primary language. Consultations with people from CALD backgrounds consistently emphasised the importance of information being made available in community languages, whether online or through print media.

Access to bilingual support workers was also identified as a priority during consultations with CALD communities, whether Ability Links NSW coordinators, support planners or disability support staff. The ability to access interpreters who can facilitate queries about disability supports and services was described as vital in engaging people from CALD communities. This feedback applied to all of the information resources and other decision supports envisaged in a person centred system.

From the perspective of engaging with Aboriginal people, the key themes from the first stage of consultations related to the

need for information to be developed with an understanding of the issues and perspectives of Aboriginal people. There are cultural considerations influencing the way that disability and disability related supports are described and discussed in Aboriginal communities. Further consultation to be undertaken with Aboriginal communities will provide an important opportunity to discuss these considerations in detail in order to shape the system redesign so that it responds to the needs of Aboriginal communities in NSW.

This section outlines the main themes arising from the consultations relating to the decision supports needed to create access to information, advice and resources in a person centred system. The discussions in the consultations were heavily weighted towards decision supports as these are the resources and tools that people with disability, family members and carers identify as critical in supporting them to make informed choices, plan and coordinate a mix of mainstream, community and funded supports and services to realise their individual goals and outcomes.

Informed choice

During the consultations, people with disability, families and carers identified the need for accurate and reliable information in order to make informed decisions about supports and services.

Informed choice is characterised by a person's awareness and understanding of the support and service options that are available in their local and regional area, and relevant to their support needs. The type of information that underpins meaningful choice includes:

- Information on the nature of the support or service - what is being offered?
- The target group of a support or service, or the support need(s) to which it responds – who is it for?
- Eligibility criteria – who is able to access support?
- The quality of a support or service (for example, indicators of quality might be compliance with a particular standard) – how do I know if it is good quality?

- Access to feedback about the experience of others who have used support or service – what was the experience of other users?
- The attitude and values of the individual or organisation providing a support or service as well as the qualifications held by individual staff – what motivates this provider?
- The price of a support or service broken down into its component parts – how much will it cost?

This level of detail enables people to discern between supports and services to determine which ones best meet their needs and their relative priority.

One of the key themes raised in all stages of consultations is that it can be extremely difficult to determine the relevance and quality of a support or service in the current disability service system. Supports and services are not generally described or marketed from the perspective of the outcomes they offer to individuals, families and carers.

The majority of participants commented that there is an enormous amount of information that is unhelpful. A number of people with disability, family members and carers indicated

they felt confused about the supports and services that may be available to them.

“I didn’t know what services I was entitled to until my daughter was 18 years old.” Parent

Online information resource in a person centred system

During the initial stages of consultations, there was a strong call for an information directory to consolidate information on supports and services in one place. A key proposition in the discussion paper was the creation of an online service directory that would help people locate appropriate supports and services.

During the third stage, the option of creating an online information directory, was strongly supported. Further, there was consensus that it should contain information on mainstream services, disability related, statewide and local services.

"An information directory would be helpful for those who don’t know what they need yet." Family member

There was a strong view that the information needs to drill down to a very local level - at least to the local government

area level - if it is to be useful to people seeking supports and services.

"We need to know what it is in our local area."

Person with disability

It was also recognised that the directory would need to be designed and managed well to ensure that it is accurate, easy to use and up to date.

"The directory is only as good as the information that goes into it."

Family member

A number of participants expressed the view that government should have overall responsibility to maintain an online directory. However, some service providers thought that there was potential for a directory to work well in a market context. A more competitive market could encourage providers to maintain the directory for themselves. Service providers suggested that, in a person centred system with individualised budgets, they would need to advertise their supports and services in order to attract business. It would be in their interests to provide accurate information about their business offerings and keep it up to date. Some providers suggested that a directory could be established with protocols spelling out

the rules and requirements for content and format, update and maintenance requirements and the provision for removing providers who do not comply with these rules.

A small number of participants stated that an independent entity should maintain the directory and verify the content. Representatives from smaller organisations expressed concerns that larger organisations could devote more resources to the directory for marketing purposes with the result that they would be advantaged. However, it was recognised that a standardised approach, protocols and information format would level the playing field and allow system users to compare services more easily.

“Providing information is one of the strengths of the sector and the directory could build on this. The move to an open market will transition that strength to a point of differentiation.”

Service provider

Feedback and service ratings

One of the themes discussed during the consultations was the need for people to be able to share their experience of a support or service. Feedback from people who have used a support or service is not routinely collected or made available

to other prospective users. The majority of people with disability, family members and carers who were consulted saw value in being able to access feedback from others who have used a support or service. This is something that currently occurs through word of mouth and informal discussion among peers. However, the consultations indicate that it is an area that could be formalised as part of the decision supports included in a person centred system.

A rating or customer feedback system could be included in an online information directory.

“We should be able to compare supports and services as you would compare other products you purchase. You go online and look at what’s available in your local area and see what other people have thought of it. A rating system would help with this.”

Parent

“Safe places where families can honestly share their experience with service providers are really key.”

Parent

Service providers had mixed views on service feedback and rating systems. Some indicated that it is part of customer service and an important measure of quality. Some service representatives commented that their organisation already sought client feedback and used it to improve business

practice and update how services are provided. They also discussed the importance of complaints mechanisms within a customer service context, and the need to make clear to customers how complaints are handled and addressed. This might be through a guarantee of service or an online complaints process, which requires the provider to account for how complaints are handled directly to their customers.

Some providers saw real potential for feedback and ratings to complement their marketing activities, for example, by highlighting the features or characteristics of a service that service users value most highly.

"Feedback/service rating would inform clients and assist in the competitive market. It could be beneficial for smaller service providers who may not have the same market presence as larger service providers." Service provider

Others expressed concerns that feedback and rating systems could be highly subjective and open to manipulation in a number of ways. For example, without appropriate protocols, subjective ratings would allow service providers to rate their own services highly and other services poorly. Similarly, subjective ratings would be sensitive to the views of individuals

who felt strongly about their services, or had had a single negative experience.

The need to design appropriate reporting and accountability measures to ensure that service ratings are fair, reliable and relevant was acknowledged. There were practical suggestions to ensure the integrity of service ratings, such as using a standard and limited set of criteria or questions against which services could be rated, the use of aggregate ratings, and providing capacity for service providers to reply to feedback. There were mixed views on whether a person who wished to make a complaint or raise an issue should have to identify themselves in order to do so, given that this may inhibit people from making a complaint.

Dedicated information line

During the consultations, people with disability, family members and carers consistently emphasised the importance of being able to talk to somebody directly in order to obtain information. Online resources were seen as valuable as part of an overall approach to delivering information. However, there was a great deal of discussion about more direct forms of obtaining information, recognising that some people may not

access online resources and many prefer direct contact and the ability to 'just have a conversation with someone'.

A suggestion made frequently during the consultations was that a well advertised and dedicated information line would be helpful in thinking about a more person centred system. It would mean that a person with disability, family member or carer could talk to someone about support and service requirements and general options in the first instance. The dedicated telephone line would need to be staffed by knowledgeable people and used in conjunction with the online service directory so that they could answer queries and provide useful information on support and service options in local areas.

Opportunities for face-to-face contact at points where people might be seeking support and assistance were consistently emphasised as an important feature of a person centred system. The discussion paper outlined areas where face-to-face contact might be designed into a person centred system and these are covered in more detail in sections 2.3 - 2.5 of this report.

Peer support

During the consultations, people with disability, family members and carers consistently emphasised the importance of being able to share information and real life experiences with each other. Participants in many of the sessions noted that one of the main ways that people find out about supports and services is through talking to other people who have used them. A number of people commented that they learned more from talking to each other than by any other means. Lack of access to peer support and networks was identified as something that limits the ability of people with disability, families and carers to think beyond their current experience and imagine new possibilities.

“You don’t know what you don’t know.”

Person with disability

Currently, some service providers create opportunities for people to come together informally. Participants observed that there is a risk that these types of informal activities could be reduced in a more competitive market. There was an underlying concern that individualised funding could produce a ‘lonely’ system.

“What if the changes mean that providers stop putting on free morning teas and information nights...how will people connect with each other”? Parent

There were suggestions that the reforms could be an opportunity to rethink peer support. A number of people commented that peer support initiatives could be more deliberate and more creative in finding ways to encourage people to come together. Suggestions included providing activities outside of business hours, catering for young children so that parents can attend, and focusing on things that are of interest to particular groups of people (for example, fathers). Suggestions for government to facilitate peer support included online support, discussion groups and blogs, promoting real life success stories that help people to think differently about what might be possible, and hosting regular events designed to engage a broader range of people with disability, family members, carers and service providers.

In the context of the person centred reforms, there was also support for government to promote the changes in order to prepare and educate people about how the new arrangements will work. It was also suggested that government had a role in

funding support groups and fostering social capital and peer networking initiatives directly.

Capacity to share personal information

A consistent theme during the consultations related to the frustration experienced by many people in having to retell their story to different government contacts and service providers in the current disability service system. Many participants saw enormous value in a mechanism that would allow the appropriate sharing of some personal information on a consensual basis, for example, through the creation of a centralised client information database.

“It is so frustrating and demoralising to have to repeat yourself over and over again. My daughter can’t walk ...she will never walk yet every time we need a new wheelchair I have to start from scratch and justify it.” Parent

The discussion paper proposed the creation of a centralised client information management system. This would allow individuals to view their own support requirements and history, their personal plan and funding allocation and share all, or some of that information, on a consensual basis.

Participants in both the individual and service provider consultation sessions were overwhelmingly in favour of a client information management system and felt that it would be a useful tool that would make life easier for people with disability, their family and carers who are seeking access to supports and services.

“It would be so good if some of our information could be accessed by service providers so services can work together.”

Parent

“Currently lots of time is spent on trying to get information from a client before you can offer them a service. It would be much easier if this information could be contained on a central system.”

Service provider

Participants identified the type of information that could be included on a system and shared with consent. This included basic information such as name, contact details, date of birth, gender, information about a person’s disability, support and service history, supports and services currently accessed, and the outcomes sought through a personal plan. All participants strongly supported clear and rigorous privacy controls to govern access to a client information management system and use of the information it contains. Participants in the

consultations also raised some concerns that information sharing could lead to discrimination against people with challenging behaviours or complex support needs. Protocols and privacy controls supplemented by effective complaints mechanisms were identified as measures to reduce this risk.

“The client should have control over who is able to access their profile and be able to turn that access on and off.”

Service provider

Some service providers saw value in being able to share information with other providers through a client information management system. In particular, providers thought that this may be a useful tool to share their insights and experience so that, collectively, all the people supporting a person were consistently working towards the same goals. This would assist providers to configure support and service options for people to choose from, including referral to other providers that would better meet their needs.

“If we could input information into the database it would help us and other providers to understand the needs of the person so that we can work out how best to support our clients.”

Service provider

Access to mainstream and community supports and services – Ability Links NSW

During the 2011 consultations, people with disability, family and carers emphasised that mainstream and community supports and services should be as accessible to people with disability as any other person. A number of people expressed the view that much more could be done to remove the barriers that prevent people with disability from accessing mainstream services and participating in employment, community and social activity. This was considered a necessary complement to reforms to disability supports and services.

“There is a need for broad community services to be accessible to meet everyone’s needs. Some specialist services and supports will still be needed to complement the broad community services.”

Parent

Participants identified a strong role for Ageing, Disability and Home Care (ADHC) in advocating, educating and supporting other mainstream agencies to become more inclusive of people with disability and focused on the outcomes for individuals, families and carers. The areas identified as

particularly requiring collaboration within government included health, housing, education and transport.

The discussion paper described the introduction of Ability Links NSW coordinators and the role of these coordinator positions in a future person centred system. The NSW approach to local area coordination has been informed by the success that these roles have had in other Australian states and overseas.

The Ability Links NSW program aims to improve access to mainstream supports and strengthen community inclusion in NSW. During the consultations, Ability Links NSW was welcomed as a resource that would help people gain access to mainstream and community services. However, participants expressed concern about the exact nature of the coordination role and wanted to understand how it would work in practice. The concerns focused on what the coordinators would actually do on a day-to-day basis, and how they would prioritise the different dimensions of the role.

The general view was that the role should include:

- providing information, advice and guidance about where to access the types of supports and services that will help

(whether mainstream, community based or to be purchased with individualised budgets)

- trouble shooting and resolving blockages of access to mainstream supports and services
- raising systemic problems in accessing mainstream services, for example, health, education or transport services, within ADHC so that it can be taken up at a higher level across government
- developing relationships that open doors for people with disability (for example, creating relationships with potential employers and community support organisations)
- providing a point of face-to-face contact with the disability service system, and
- referral for people whose needs are not able to be met through improved access to mainstream and community based supports and services and who require disability related support funding.

A number of Ability Links NSW coordinators will be Aboriginal identified positions. Consultations with representatives of CALD service providers strongly identified the need to have similar CALD identified coordinators strategically located

around the state. This was considered necessary to ensure that people with disability from CALD backgrounds are equally able to access information and advice and connect with supports and services.

Feedback during the consultations on the coordinator role noted that the role is very wide ranging. A number of people commented there is a risk that the coordinators could be overloaded due to the unmet demand in the current system and the numbers of people likely to seek assistance. It was suggested that the role of a coordinator needs to be clearly communicated so that it is not confused with other forms of support within the system, for example, planning. In reality, there is a view that people with disability, families and carers will approach coordinators for assistance whether or not their support needs are able to be met from mainstream and community based supports and services.

In addition, there was a strong view that the Ability Links NSW coordinators need to have a good local knowledge of services and supports in communities. While people welcomed the intent and directions of the initiative, people expressed concern that the coordinators might be spread too thinly to meet these expectations.

Access to disability related funding, supports and services

During the 2011 consultations, many people with disability, family members and carers said that the current disability system is difficult to navigate. People provided accounts of how difficult they had found it to determine where to go to access support or even start the process of having their eligibility for support and detailed support needs assessed. A number of people expressed the view that eligibility requirements were currently unclear and that the assessment process itself could seem inconsistent and unfair in its outcomes for individuals.

The discussion paper described the need to improve access by providing:

- clearly identifiable points of contact and access to the disability system (including a dedicated telephone access, online access and physical places to walk in and meet face-to-face)
- clear and fair eligibility criteria
- consistent and transparent assessment processes and

- appropriate appeal process for a person who is not satisfied with the outcomes of an assessment.

These were focus areas for discussion during the final stage of consultations.

Points of contact and access

Discussions around access focused on the need for practical and flexible approach to account for the varying needs and requirements of people who will seek assistance.

There was agreement on the need for access to provide:

- a clear point of access to information and advice on disability related supports and services
- referral and access to relevant mainstream and community based supports and services as well as access to disability supports and services
- screening to determine a person's level of disability related support needs broadly and their eligibility for funded disability supports
- detailed assessment of support needs to form the basis of a funding allocation (individualised budget) with which a

person can then purchase supports and services (directly or through an intermediary) and

- referral to case management or crisis support as required.

There was a great deal of discussion around the best ways to provide points of contact and access and the relative benefits of:

- physical infrastructure - regional and local offices so that a person with disability could 'walk in' to initiate an assessment of their eligibility for support and support requirements
- a dedicated telephone line - which would be of particular assistance to people who are less independently mobile and
- assessors who are able to travel to people's homes to assess eligibility and support needs - which would be particularly useful for people living in regional and remote areas.

Overall, the dominant view was that a mix of approaches would be needed to ensure coverage in terms of the geography of the state and the varying requirements of the people who may require support.

In addition, there was recognition that the initial start up stage of Ability Links NSW could generate a spike in demand for referral to access points for eligibility screening and assessment for disability funding. The inter-relationship between Ability Links NSW, mainstream and community supports and the access points and processes that will govern eligibility for individualised funding would need to be carefully managed, with clear communication and referral between the two.

There was a strong view that people who already receive disability supports and services should not have to go through an assessment process in order to transition to the person centred system, unless they wish to review their current access to funded supports and services or their circumstances change. There was also a view that the system should provide avenues of appeal for a person who is unhappy with the outcomes of an assessment.

Eligibility

During the consultations, people with disability, families and carers expressed concern about current eligibility criteria and requirements, and the need for clarity around the rules that govern who is eligible for funded support. There was a strong

view that current eligibility criteria are not clear and this needs to be addressed in moving to a person centred system.

Building on these observations, participants identified the importance of clarity around who is eligible for disability funding in NSW now and in a reformed, person centred system in the future. Unmet demand is a significant issue. The 2011 Productivity Commission report noted that the significant levels of unmet demand that exist within the Australian community would only be able to be addressed through the creation of a NDIS, drawing on pooled resources and spreading the risks and costs of disability related supports across the whole community². NSW is not considering expanding eligibility criteria, pending a NDIS. However, the feedback that NSW eligibility criteria and guidelines should be clearer, fairer and applied consistently is being considered in developing options for improving access and assessment.

The majority of people who were consulted recognised that (in the absence of a NDIS) NSW has finite resources and must prioritise supports and services to assist those in greatest need.

² Productivity Commission (2011) *Disability Care and support*, Report no. 54, Commonwealth of Australia: Canberra.

Assessment of support needs

Needs assessment is the process through which the support needs of a person with disability are considered and understood. Assessment is the basis for a determination of the level of resources, supports and services required. Currently, assessment processes in the NSW disability system are very different, and program or organisation specific. There is no single consolidated needs assessment process to determine a person's overall disability related support needs and to link a funding allocation to those needs. Similarly, there is currently no clear point of appeal for a person who is unhappy with the outcomes of an assessment.

People with disability, family members and carers identified the need for reforms to the assessment process so that it is based on consideration of a person's support needs and requirements rather than their disability. Currently, the common view is that assessment is reliant on a diagnosis. This is particularly problematic for families with young children who have disability related support needs but no formal diagnosis, or have inconclusive diagnoses. These families report finding it very difficult to access supports and services or funding in the absence of an official diagnosis despite the fact that their child has obvious support needs.

“Assessment of support needs would be better than assessment of disability. The process should look at a person’s support needs rather than ticking a box.” Parent

A number of participants in the consultations observed that assessment is fundamental in terms of ensuring that the system is fair in how funding is allocated. A centralised assessment process based on determining a person’s support needs and strengths would be a significant improvement to current arrangements. This could link various health and disability related assessments together, but under a framework that is directed towards understanding a person’s support needs rather than categorising a disability. Assessment was identified as something that requires more than a checklist approach. There is a strong view that it should be based on a real conversation.

The need to develop (and the difficulty of developing) a consistent and coherent approach, framework and tools for assessment was recognised. It was also recognised that the NDIS process is considering ways to develop more holistic needs assessment frameworks and tools and that NSW should avoid duplication of this process where possible.

Person Centred Planning

Many of the people who were consulted commented that they place a high value on being able to sit down and talk to someone who understands the system and can provide independent advice. The majority of people with disability, families and carers saw face-to-face discussion with someone who knows the mainstream and disability sector and can help with planning as one of the most critical decision supports.

From a system design perspective, this means changing the way that planning is done and providing resources and decision supports to help people participate in it. The key reform here is to provide access to planners. These would be skilled and competent people who can facilitate outcomes for people through planning by providing independent advice on different options without selling a particular option.

A person centred planning process considers the supports and services that a person with disability needs in order to live their life well by their own definition. In this context, there is strong support for a planning process that considers the best mix of supports and services to meet a person's assessed support needs and contribute to the outcomes they wish to achieve in their lives. A number of people during the consultations

indicated that currently a person with disability can have various care and support plans without any consideration of the place of these plans in their overall quality of life.

The majority of people suggested that a personal plan would need to take into account mainstream supports, community participation and goals for development, training and employment as well as funded supports. The plan should seek to integrate a person's supports and service requirements into a 'bigger picture', and provide some of the overall strategy to meet these agreed bigger picture goals.

A theme that was emphasised in all consultations was that a personal plan needs to be flexible, reflect a person's goals and aspirations and also be realistic and achievable. The plan would be a living document able to be adjusted and changed at different life stages and when circumstances change.

“A true person centred process takes into account not just needs and strengths, but dreams and aspirations. At some stage it needs to involve all stakeholders to facilitate that person meeting their dreams and aspirations and to ensure that everyone's on the same page in meeting that person's dreams.” Service provider

When considering who would be involved in person centred planning, the majority of people with disability, their families, carers and service providers indicated that they thought a person should be able to choose who carried out planning. However, some people had concerns that conflicts of interest would arise where service providers were also involved in planning.

“If the planner is a service provider there is a risk that they will just recommend we use their service.” Parent

For some people, a plan might involve only mainstream and community supports, and an Ability Links NSW coordinator would be able to help them to access these services and plan for their future. Others will require more extensive, specialised or complex support and may develop a more detailed plan. For these people, a skilled planner might be the most appropriate support to help plan for all the types of supports they need.

There was some concern that if planning was carried out by service providers, they could encourage people to plan around the services that they offer rather than designing supports and services around the individual and thinking more broadly. Stakeholders observed that, while service providers may offer valuable insights into existing disability services, they may not

understand the full range of other services available in the community. As such, a common theme in consultations related to the need for independence in planning to ensure a plan is tailored to the needs of individuals and is free from bias.

“An organisation would perhaps know the person better than an outside agency, but you wouldn’t want them pushing for something that suited the service rather than the person.”

Parent

While there was strong support for independence in the planning process, there was also support for service providers to be able to offer planning services if a person chooses that option. Some people with disability indicated that they had a good relationship with their service provider and would feel comfortable working together to create a personal plan.

“If a person has grown up with a service and already has a trusting relationship with the organisations why would you suddenly sever that? There shouldn’t be any problems with either having the service involved or the person choosing to use a different planner.”

Service provider

Service providers observed that they were well placed to help people to develop personal plans and, in fact, already helped

people to plan. Some service providers distinguished between the 'high level' planning around individual aspirations, goals, types of supports and selection of providers from the detailed planning around how each of the supports are to be delivered. They saw greater need for independence in high level planning but not in the detailed support planning where input by service providers would be most critical.

Regardless of whether stakeholders saw a role for service providers in planning, they identified strongly with the view that people with disability, together with their families and carers, should have a choice about who they wish to include in developing their personal plan.

The final issue relating to planning concerned funding – how the planning would be resourced. People with disability, families and carers acknowledged the value of undertaking planning well, but expressed concern about how much of a funding allocation would potentially be consumed by planning. There was strong support for the government to fund planning in order to ensure that sufficient resources are committed to planning and to ensure value for money in terms of the way that funding is then used. If the plan is good, it will deliver outcomes for the person and outcomes for the system.

Summary of views on decision supports

Key themes

- A person centred system needs to provide access to information through:
 - online information
 - information in formats that are accessible to people with sensory impairments
 - service directories that go to a local level of detail
 - a dedicated information line/service
 - access to knowledgeable professionals who can assist a person to discern and determine the mix of supports and services that will meet their needs
 - community languages and Aboriginal and CALD identified support workers
- Ability Links NSW coordinators could be a valuable resource in the reformed system, but their role needs to be clearly stated and expressed so that they are not overloaded in the start up period.

Key themes

- The eligibility criteria for governing who will receive funding from the specialist disability system needs to be clarified and clearly stated up front during the transition to a person centred system.
- Assessment of support needs to be consolidated and redesigned to focus on support needs rather than a diagnosis or the characteristics of a disability.
- People need to know what their options are if they are unhappy with the outcomes of an assessment.
- Access to skilled planners who can facilitate outcomes by providing independent advice on different support and service options is fundamental to the success of the reforms.

4. Funding and Support Coordination

Introduction

The NSW Government has made a commitment to introduce individualised funding by 1 July 2014. This is a significant reform that will drive change throughout the disability service system. The discussion paper outlined a range of proposed reforms to funding to provide choice and control over the use of available funding to people with disability, family members and carers. The discussions during the final stage of consultations focused on the shift towards individualised funding, particularly the options for fund holding and managing and coordinating supports. Key issues for discussion included draft principles governing the use of funding and the accountabilities of individuals, service organisations and government under the new arrangements.

What arrangements would be required in a person centred system

Currently, the majority of funding for disability services goes directly from the NSW Government to disability support and service providers under contractual arrangements. This

funding is used to fund support and service types and places. The introduction of individualised funding, where funding is attached to a person with disability rather than to an organisation, represents a significant shift in the way that people with disability are able to access supports and services, and in the way that service providers financially manage their organisations.

Under the reformed funding arrangements, the pathway for a person with disability seeking funding would be:

- screening to determine eligibility for funded support
- detailed assessment of support needs
- development of a personal plan to step out the supports and services that would meet those needs and ultimately
- an allocation of funding (individualised budget).

A funding allocation would be made in relation to the individual in the form of an individualised budget so that planned supports and services are able to be purchased directly or through an intermediary on a person's behalf.

There is support for the move to individualised funding and recognition that it provides people with disability, family

members and carers much more control and certainty in relation to the resources they are able to use to access supports and services. A strong and consistent message throughout the consultations was that nobody should be worse off as a result of reforms to disability funding. Family members and carers discussed how hard they had fought to get support for their family members, and raised concerns that they could lose some of their current access to services as a result of the proposed reforms.

During the consultations, some participants indicated that there are supports and services that should continue to be funded directly by government, in particular, supports that relate to diagnosis, early intervention, early childhood supports and advocacy services. Some people considered that individualised funding may not be an appropriate or effective funding model for services that require considerable infrastructure and investment.

“Services that involve heavy amounts of capital are not flexible enough to set up or maintain without block funding.”

Service provider

Some service providers commented that funding certainty had enabled them to provide additional services and supports that

increase social capital within communities. They questioned how these benefits would translate and continue under an individualised funding model.

“Carer support and sibling support won’t be in the packages but they build social capital. These are currently able to be funded by the buffer that services have been able to build up through good management of block funding. These benefits shouldn’t be disregarded. How will these opportunities translate in the new funding system?” Service provider

Other providers stated that they were not concerned about the transition and that they were already developing new service offerings and approaches. They commented that a more flexible and outward looking approach increased business viability because it responds to demand. Brokering supports rather than delivering a set menu of services was raised as a theme. The key change was described as a change in thinking within the service provider sector. The shift in focus to the outcomes a person with disability is seeking to achieve was seen as the driver for change because it opens up possibilities in terms of the types of supports and services offered.

Options for managing funding – individualised budgets

In an individualised funding environment, a person with disability has control over the use of disability support funding. A key theme arising from the 2011 consultations was the need to recognise that people are in different places in their willingness and confidence to assume direct responsibility for a funding allocation and management of an individualised budget.

The feedback is that people will vary in their desire, ability and confidence to take on responsibility for managing an individual funding allocation and individualised budget. As such, a variety of options were proposed in the discussion paper to provide that flexibility in the system. The options range from receipt of a payment directly and self management of an individualised budget to third party management. Where a person chooses to remain with their current service provider, funding could potentially be allocated to the provider directly on a person's behalf. The key difference in the system is that the funding will be portable so that the person will be able to change service providers if they wish, taking their funding allocation with them. The funding must be used to achieve the outcomes that have

been identified through a person centred planning process, regardless of who is managing it.

This flexibility in providing options to suit different people was strongly supported in all consultations. It was also considered that this would allow people to grow into the role, to the extent they wish, over time.

Principles of individualised funding

A key theme arising from the 2011 consultations was the need to be clear about the appropriate use of disability support funding in an individualised funding environment. On that basis, a set of draft principles for the use of individualised funding was put forward in the discussion paper. The consultation sessions were used to road test and refine the draft principles, which were:

- Funding can be used to purchase disability related supports and to achieve outcomes identified in a personal plan.
- Funding cannot be used for:
 - income for the person, carer or family
 - ineffective or harmful supports
 - supports (normally) provided by another government service or agency, or
 - illegal activities.

Overall, participants agreed with the draft principles. They welcomed a clear set of principles or ‘rules’ and indicated this would provide confidence to people managing their own funding.

“People who could manage their own funds may be scared about doing it without clear guidelines, because it’s public money.”

Service provider

However, in many of the consultations, participants noted that the principles lacked sufficient detail. There were concerns that more detail was needed to understand whether innovative ideas for supports and services that do not fall into the traditional view of a disability support would be permissible. It was suggested that a number of case studies be developed to demonstrate how the principles would work in terms of what would or would not be permissible under the new system. Real life examples would help people to understand the rules.

Discussions during the consultations also centred on what constitutes a reasonable use of public funds more generally. Most participants considered that while not illegal, spending on gambling, alcohol or tobacco would be inappropriate. However, some participants cautioned that prescriptive

limitations should not become barriers for people to expand social opportunities.

“I want to be able to use my money on what I want to and not be told I can’t spend my money on certain things. If I want to use some of the funding to go out to a club with a friend, I should be able to.” Person with disability

The principle of funding not being able to be used for other services provided by government was agreed as necessary for the integrity and sustainability of the system. However, most parents, carers or people with disability who provided feedback around this principle spoke from personal experiences in trying to access services across different service systems and observed that these services were not always appropriate or sufficient. In particular, participants identified education services, such as home schooling and tutors, and the purchasing of equipment and aids (available through Enable NSW) as requiring supplementary investment. There was concern that the principle could prevent people with disability from achieving their outcomes for quality of life, for example, in situations where there was a long wait time for an essential piece of equipment. The suggestion was that the principle be

modified to allow flexibility where a person could demonstrate the benefits of the expenditure to their quality of life.

"Supplementary services should be provided, even if a service is provided by the government, if that provided service is not sufficient." Carer

The draft principle that funding should not be able to be used for ineffective or harmful supports was also discussed during the consultations. This principle aims to protect service users from unscrupulous agents offering supports and services that have little or no effectiveness. While participants recognised the intent of the principle, there was significant discussion about how 'ineffective' and 'harmful' would be able to be determined.

"Who decides what is ineffective and harmful?" Parent

It was also unclear who would decide what constitutes an ineffective or harmful support in an open market where supports and services could be purchased from a broad range of providers. The consensus was that this principle needed more thought in terms of its workability.

A number of stakeholders also suggested that the principles be expanded to include the provision for funds to be rolled

over. There was strong support for the ability to roll over a proportion of funds to allow people to 'save' for more expensive services or goods.

“If you haven't spent all your money in a period you should be able to roll it over into the next period. This would encourage people to be innovative and efficient.” Parent

Employing your own support staff

In a person centred system built on choice and control, it could be possible for people with disability to choose and hire their own support staff. This was discussed at length during the consultations.

A number of people with disability, families and carers were enthusiastic about directly employing staff to support them. They viewed this as an important feature of individualised funding. For them, it would provide the ability to engage and train support workers in a way that works best for them.

“I want to be able to choose a support worker who is like me. They will be with me day in day out and I'd like to get along with them.”

Person with disability

“It is important that the person who works with my child is able to integrate into our family - they are part of our family life and I want to choose who comes into our home.”

Family member

Others expressed concern that employing staff directly would be difficult and time consuming for people with disability, their family members or carer.

“If you expect people to do all that then you’re going to have to give them a lot of input. It’s a minefield and in the end you pick it all up and you give it to a provider because it’s too hard.”

Parent

The key issue related to understanding the requirements associated with becoming an employer, and how to go about arranging insurances, workplace health and safety assessments, employment contracts, consumer protections (for example, fair trading provisions), working with children checks, police checks, tax and superannuation. People indicated that they would need information about industry standards such as wages and conditions, qualifications, work health and safety and assistance to ensure that they were complying with relevant regulations.

“I would like support to know the work entitlements of staff and help with making sure I am meeting the responsibilities of being an employer like payroll, insurance, work cover, superannuation, etc.”

Person with disability

There were practical suggestions for day-to-day supports that could be developed for people wanting to directly employ their own staff. These included guidelines and resources to help people take on the role, set up assistance, mentors, training, online resources and an ability to seek advice on employer-employee requirements. A number of participants suggested that the onerous, and potentially expensive, requirement to have multiple insurances could be met by government facilitating a collective, ‘umbrella’ policy.

Service providers had concerns around people with disability, their family members or carers taking on an employer role traditionally filled by them. Their concerns centred on quality - support workers could be directly employed without undergoing the same quality processes and training that service organisations require. Some service providers were also concerned that direct employment could result in staff being hired for less than organisations could viably compete with. Service providers argued that people purchasing services

may focus on the price, as opposed to the quality (training, insurance cover and qualifications), of the service providers they engage. This could create risks to people with disability as employers, as well as the risks to employees themselves in terms of workplace conditions and the risk of injuries.

“In the new model people will be more focused on costs. If they can get it cheaper from an informal approach that doesn’t need to meet requirements, NGOs will be undercut unless everyone has to comply with the same regulations and standards.”

Service provider

Payment of family members

In the first stage of consultations, people spoke of the potential benefits and risks associated with allowing individualised budgets to be used for the direct payment of family members or carers who provide supports and services. There were divergent views on this in the final stage of consultations.

People with disability, their family and carers who support payment of family members generally do so out of recognition of the care and support that family members and carers provide.

“You have short notice of a function and you have a family member willing to provide care and support so that you can attend, sure they’ll do it for nothing but why shouldn’t they be paid instead of a service that costs twice as much?”

Parent

Support for paying family members also focused on the notion that family members and carers are often the most appropriate provider. This reflected the familiarity and rapport that relatives brought to relationships with people with disability. Having the option of being able to pay family members attracted strong support in rural areas because of the more limited choice of service providers in those locations.

“Family members know the person well and in most cases they can stay in the home with them. It negates the need for respite and the risk of having strangers in the house alone with the person. Some people will not go to strangers, and have anxiety over being left with strangers.”

Parent

Those who did not support payment of family members noted the complications that could arise from ‘commodifying’ family relationships, in particular, the potential difficulties that could arise where relatives are formally engaged as service

providers. These might include challenges in negotiating workplace performance, terminating the arrangement or changing the service provider.

“I’m not totally happy with paying family members as it would change the dynamic between a freely given relationship and a paid relationship...I just think it creates a lot of issues.”

Parent

A number of participants also had concerns that family members might become financially reliant on, or exploit, the person with disability’s individualised funding package. Further to that, choosing to engage family members as service providers may reduce a person’s choices in terms of their social interactions outside of their family, and their ability to live the life they really want to live.

There were participants who thought that paying family members was reasonable, provided that appropriate safeguards were put in place:

"Payment of family members is reasonable, so long as the person with disability is not being exploited."

Family member

These safeguarding measures might include a case by case or exemption based approval process for family members being paid, restricting payment of family members to low intensity care and supports (for example, accompanying a person to a recreational activity), or paying only the cost of the expenses that a person incurs while providing care or social assistance to a person (for example, movie tickets).

Payment of family members was identified as an area that requires more thought and could be initially tested on a small scale.

Accountability for the use of funds

In an individualised funding system, a fund holder is the party that chooses, or is nominated, to receive individualised funding allocation and budget. Under the arrangements proposed in the discussion paper, the fund holder might be a person with disability, a family member, carer, or service provider. The consultations provided an opportunity to discuss the accountabilities that would need to be in place around the fund holding role.

Participants throughout the consultation process overwhelmingly agreed that whoever chooses, or is

nominated, to take on this role would need to demonstrate accountability for the use of funds to achieve the outcomes sought in their personal plan. Government was also seen to have an oversight responsibility:

"Government responsibility for checks and balances should continue as funds are essentially Government's asset. These need to be in place regardless of who is fund holding." Service provider

There was overwhelming agreement that individualised budgets need to be used for enhancing the lives of people with disability and for the purchase of services and support to achieve the outcomes agreed in a person's plan.

"The money needs to be handled correctly and used to enhance lives and improve people's choices. We need to be really accountable on how people are spending their money. Yes the Government needs to support us, but where do we draw the line and where does the bucket end?" Parent

Family members, carers and service providers expressed the view that a simple but credible accountability system should be in place to ensure that individualised budgets are used appropriately:

“We’re working on the basis that every parent is a good person...but there needs to be some checks and accountability.”

Parent

When people were discussing the concept of accountability and what this might look like in reality, the discussion focused on the tension between accounting for the use of funds, and being overburdened by accountability requirements.

Throughout the discussions, family members and carers consistently made the point that they are time poor. Caring for a person with disability is their primary priority. If any of the reforms require an unreasonable amount of time and micro management, then they would be unhelpful for people with disability, their family members and carers.

“We’re looking for something that doesn’t give us too much responsibility.”

Parent

Having an overly complicated accountability system might be off-putting to people when they think of being the fund holder for an individualised budget, and could outweigh the benefits of self management.

In terms of the requirements for accountability, participants made practical suggestions that would help people to manage funds appropriately, including regular, payment periods (for

example, quarterly), training in financial management and set up assistance, as well as practical tools such as budgeting spreadsheets and guidelines. A number of people suggested that funds could be paid at periodic intervals into dedicated bank accounts. There were also suggestions that the government could enter into negotiations with financial institutions to provide fee free bank accounts for this purpose. Alternatively, it was suggested that funds could be made available through dedicated debit cards. These suggestions would separate a person's funding streams, and would assist in accounting for the funds and their expenditure.

Calls for accountability extended to service providers. Family members and carers discussed how difficult it was in the current system to determine how service providers spent money, and how that money was used. A common frustration family members and carers had was that it had been difficult for many family members and carers to get exact information about the proportion of funding that was spent on administration, and how much on services.

“It's not transparent enough for us to know. We don't know and we don't know the questions to ask to know.” Parent

The call for transparency throughout the entire process, from comparing services to fund management, was repeated throughout the consultation process. This reflects the strong view that there is a lack of transparency currently being experienced by users of the disability system. Given that fund holders would in some way be accountable for budgeting and expenditure of individualised funds, there was an emphasis on service providers being transparent with this type of financial information.

“I would need information about how the cost is broken down. You need to know where every dollar is going because you’re going to be accountable for it.” Carer

While the discussion focused on accountability, the majority of participants expressed optimism that individualised budgets would be used not only appropriately, but in a more effective way than resources have been used under the current system. People with disability, their family members and carers who had been involved in existing programs that use an individualised funding model were vocal in their optimism for people managing their own funds.

"Countries like England find that people are responsible for their own money and are very ethical. Lots of people return a surplus."

Person with disability

Skills and capacity

Another strong theme of the consultations was the need to support people to develop their own capacity to be a fund holder. Willingness and ability to manage an individualised budget may be influenced by a number of factors such as the time available to perform this role, decision making skills and understanding the responsibilities of the role. Some family members and carers were concerned that they would not have the skills to be able to perform this role. Some expressed concerns that the person with disability they were caring for would not have the skills and experience and could 'come unstuck'.

"We want to be able to do it, we just don't think we'll be able to."

Parent

It was clear throughout the consultations that people with disability, their family members and carers wanted, and would need, support to transition into a fund holding role and increase their capacity and confidence to do so.

“People need support to understand what their responsibilities are, and need support to deal with their legal obligations.”
Family member

However, people who had had experience with self directed funding spoke of being able to self manage funds with the right support. The type of supports that people talked about included being provided with budgeting training to budget, and tools to help them manage their funding.

“She learnt how to do all the financials for her package. There is simple software now that can be used and set up for the person with disability to manage their own finances.”
Parent

Participants suggested that, with the right supports, a person could grow into the role and take on greater levels of choice and control over time. Similarly, if a person’s situation changed and they needed to reduce the level of responsibility they were exercising in terms of self management, the system should allow for this before it reached a crisis point.

"The roles need to have enough flexibility to cater for changes in the capacity of the people in these roles to effectively do them"
Service provider

Summary of views on individualised funding

Key themes

- Individualised funding has strong support.
- Guidelines around the things that funding can and cannot be used for need to be clear – the draft principles put forward in the discussion paper may require further development to improve clarity and workability.
- Payment of family members is contested and may be suited for small scale trial in the first instance.
- Accountability requirements need to be strong but simple.
- People will need a range of practical supports in order to assume the roles of fund holder and coordinate their own supports.

5. Service quality and supporting the sector to transition

Introduction

Moving to a person centred system will allow people with disability to purchase a broader range of supports and services, and provide direct financial incentives for service providers to do things differently. Demand for flexible and responsive supports and services will drive innovation. During the consultations, there was overwhelming support for change and innovation to occur but concern about ensuring the quality of services in a more open market. Some consultation participants saw a need for government regulation to support and ensure quality while others expressed confidence in a market driven approach where the provider is directly accountable to the customer. This section outlines the main themes from the consultations regarding sector support and maintaining quality.

Regulation to underpin quality

Many people saw an ongoing regulatory role for government in a person centred system. They viewed quality standards and

regulation as an important foundation in a person centred system.

“People with disability are the most vulnerable people in society; the government should regulate services.”

Parent

A number of people consider strong minimum standards and industry regulation should apply to disability support and services. This would include requirements for training and qualifications for particular occupations, work, health and safety and criminal background and working with children checks.

“Some benchmark has to be set as a bottom basic standard that we can all expect within a community, not just for people with disabilities.”

Parent

Market forces as an incentive for quality

Many people were confident that the market would self regulate quality when providers were made more directly accountable to their customers. They pointed to individualised funding as providing the opportunity for people with disability and families to move to a service that suited them and

responded to their needs best - as long as a meaningful choice exists.

In a more accountable market driven environment, it was felt that services would provide high quality services that respond to people's needs to ensure that they attract business.

“My suggestion is that the government shouldn't have any regulatory control because self managed funding is individualised and therefore portable. If I don't like the service Lara is giving me, I say “thank you Lara” and then go to Lisa.”

Parent

Additionally, by turning the traditional funding relationship 'on its head', services would become accountable to individuals rather than government. This would enable the contract for service to be between the person with disability and their family. Some view this as an opportunity for people with disability to have a more direct conversation with their service provider on the quality of service, flexibility and other aspects. This agreement would then drive and ensure quality and, if a person was not satisfied, they would be able to change provider much more freely.

Preferred provider lists

Some viewed government regulation, such as the practice of government developing an approved service provider list and requiring supports and services to be sourced from that list, as a restriction on choice. Limiting choice to a predetermined range of options was seen as working against a person centred approach and social inclusion.

“Personal choice of services needs to be unhindered by bureaucratic red tape.”

Parent

“When my daughter who doesn’t have a disability goes for dancing classes I don’t have the government regulating it and seeing if it’s top quality or not. It shouldn’t be any different for my other daughter with a disability. I don’t want her to be made to feel ‘different’ and have special regulations that services have to comply with just for her.”

Parent

Additionally, some service providers and families identified government regulation as restricting their ability to provide flexible services and solutions. They would like to be able to think outside the box and be innovative.

Risk based regulation

People with disability, families and carers agreed, in the main, that there may be some limited role for government to regulate the quality of specialist disability services. This is because of the vulnerability of some people with disability (for example, in a group home setting) and the specialist skills required for some types of service delivery.

“Specialist supports and services need to be regulated because of the part of the community that they’re dealing with.”

Parent

“You want the person helping you to know what they are doing. You want to make sure that the person using that piece of equipment is trained in OHS or is even able to pick me up if I fall.”

Person with disability

There was a view that some types of supports and services were higher risk and potentially warranted more stringent regulatory control and standards. There were divergent views about whether regulation needed to apply to community based supports and services.

“People should be able to use their funding on community activities. I’m worried about the possibility of ADHC doing

an assessment of a bowling alley a person with disability wants to use. People should be able to choose to use their funding on things like this even if the organisation doesn't meet disability sector standards." Service provider

A number of people in the consultations discussed the adequacy of basic consumer protections and their ability to lodge complaints with government and consumer bodies and to take other action in support of their rights. Others spoke of the importance of being able to try new things, including choosing supports and services that may not be of the highest quality but that suited their needs and budget.

Some service providers on the other hand expressed the view that government regulation of some types of supports and services could create an uneven playing field in a competitive, market driven environment. They were similarly concerned with the different expectations, and cost, that will exist for services as against new providers, for example friends employed directly by a person with disability.

In summary, the perspective of most stakeholders was that government should regulate services that involve high risk and enable choice and control to work to regulate quality for all other types of services and supports.

Ensuring quality for people who employ supports directly

Some people with disability, families and carers discussed their desire to employ people directly without going through a service provider or labour hire company. Some would like to employ friends and family.

Stakeholders questioned the regulations that would apply to employing staff directly. They saw employing staff directly as offering a 'real' person centred approach that would allow them to select, train and work consistently with a particular individual. Some saw this as a way to 'make their money stretch further' than if they used established disability support and service organisations. However, concern was expressed about the extent of the regulatory requirements to which they would potentially need to adhere in choosing to directly employ staff. Work health and safety, insurance, superannuation, tax, staff training and other employee entitlements were identified as areas that would be overwhelming for some people with disability and families to manage. Some felt that their funding should not be consumed with these perceived administrative aspects.

“I know what I want. If I could employ my own staff to do the cleaning and set the times it would work so much better for me. But I don’t want to have to use my funding for insurance.”

Person with disability

Other stakeholders, including service providers, expressed concern that the quality standards and conditions for staff in the sector could be undermined if people with disability and families were not required to adhere to the same standards as other employers in the sector.

It was generally agreed however that the existing legislation, regulation and quality accreditation processes could be onerous for a sole-trader or a person with disability or their family to manage. Information and training for people wishing to employ staff, or be employed, directly would assist to overcome these barriers. This could be provided in a range of online, face-to-face, printed and telephone formats as previously discussed in relation to decision supports.

Information about quality in a person centred system

Information about the quality of services and supports is important for people with disability, families and carers when

making decisions about which supports and services to purchase. This information needs to be available in a range of accessible formats - online, face-to-face, print media and through telephone contact. During the consultations, people with disability, family members and carers indicated that information about quality should be provided in a way that is meaningful to them and reflects the things that they see as priorities.

“Standards are used for clients as shorthand to know that they’re getting a quality service. Quality standards need to be marketed well – something like the heart tick of approval. Consumers need to be educated about these standards so they can make the best choice when choosing services.”

Service provider

Some suggested a service user ‘star rating’ system, surveys or an independent quality review.

“It would be good to have a one-stop-shop online where you can get information on services – but also about the quality. This could be done through peer reviews of services.”

Parent

There was broad support for the use of feedback about service quality to direct change in service provision.

“If I move service providers because one is not high quality I should have to tell the government what I’ve done so that they can see there’s an issue there.” Parent

Summary of views on quality in a person centred system

Key themes

- There are divergent views about a ‘one size fits all’ approach to regulation and quality assurance in a person centred system.
- There is recognition that some types of supports and services are higher risk and potentially warrant more stringent regulatory control and quality standards.
- The consensus is that community based supports and activities should not be regulated to the extent that it impacts on choice and innovation.
- There is consensus that a person centred system should allow a person with disability to purchase supports and services from a range of providers, with quality one consideration among others in the exercise of informed choice.

6. Transition to a person centred approach

The transition to a person centred system is a significant change and requires a considerable shift for people with disability, family members and carers and service providers. The change is philosophical, cultural and practical.

Support for people with disability, families and carers

During the consultations, people with disability, families and carers spoke in detail about the types of support that they would value from government, service providers and each other to fully participate in a person centred system. Many spoke about a desire to innovate with others in similar circumstances, to learn about what works, to learn new skills and to support each other.

In a person centred system, there were three main areas where people with disability, families and carers indicated they would like support: day-to-day, in self directing supports and managing funds, and in choosing to directly employ staff.

The day-to-day supports

During the consultations, many people were excited about the possibility for person centred reforms to change their day-to-day lives, and they indicated they would like to make the most of the opportunities. Connecting with others, learning and innovating were viewed by people with disability, families and carers as important aspects of the transition.

The expansion of networking opportunities received overwhelming support. Community events, conferences, workshops, family days, carer fairs and disability services expositions were all identified as networking opportunities for people with disability, families and carers. A number of parents suggested that these should be arranged at various times to ensure that working parents can also attend. It was suggested that events could include childcare so that parents can have the opportunity to participate fully in discussions and events. Additionally, people suggested ongoing support groups using a variety of mediums:

- face-to-face community support groups
- online interactive and social networking spaces (for example Facebook, email lists, chat rooms, and Twitter)
- teleconferences

- Skype online video conferences.

Support groups could be focused on providing emotional support to members, innovating solutions to commonly faced problems or to make the most of the opportunity individualised funding presents. They could also be focused on creating a supportive learning environment.

“I want to get together with other parents and work out how we can support each other. We have the opportunity with individualised funding to think up new ways of how we can support our kids.”

Parent

Many indicated they would like to learn more about person centred approaches through having the opportunity to read about other people’s experiences in blog posts on websites (ADHC, service provider and other sector sites) and engage in a conversation.

“My ideas have come from listening to families who have done it from other states. It seemed really scary at first, but now that I’ve heard other people who’ve been doing it for years it isn’t as scary. I was able to listen to the tips and traps – it’s a useful way of knowing how to go forward and make the most of the new system.”

Parent

Case studies, articles, video interviews and conferences were identified as good ways of sharing this information. Person centred champions in each community were also welcomed.

Self management of funds and coordination of supports

Making the decision to take on some or all responsibility for managing funds and coordinating supports was viewed by many people with disability, families and carers as something beyond their current reach. Many people who would like to move gradually towards self direction felt that they would need support to do this. They identified government, service providers, planners, other family members and friends and other people in their network as having the ability to provide the support they need.

In addition to the day-to-day support mechanisms and opportunities, people with disability, parents and carers indicated they would need specific tools to manage funds and coordinate supports. These included budget spreadsheets, templates to keep account of expenses and receipts, checklists for managing funds, diary tools and checklists for coordinating multiple services and supports.

“Being provided with simple accounting tools and training would be helpful”
Parent

“Government should publish bands of reasonable amounts to pay – that is, guidelines as to what to pay for services so that people have something to measure against” Parent

“I would like clear forms, guidelines, flowcharts and checklists that state what I need to do to manage funds, coordinate supports, when and how.”

Person with disability

Importantly, people indicated that once given the tools, they would need assistance in setting up the systems and understanding how to use the tools effectively.

“I would like an initial education program to help us select services and manage our funding.” Parent

Online training courses, face-to-face support to set up and troubleshoot, telephone support, workshops and online help (for example, instant messaging) were all seen as appropriate ways to support people with disability, families and carers. It was felt that a variety of resources, tools and help points will empower people to take more control of their day-to-day support and service arrangements.

“Any kind of tool used needs to be made in plain English, with pragmatic questions, nothing ‘airy fairy’. There should

also not be a barrage of forms that have to be repeatedly filled out.” Carer

Others suggested that a formal mentoring system could be developed by ADHC to provide ongoing peer-to-peer support. This could happen within a local community or anywhere in the state if telephone and online communication was possible.

Transition support for the support and service sector

People with disability, families and carers spoke of a cultural change that needs to occur in the support and services sector as a whole. A person centred system means putting the needs, aspirations and goals of the person with disability, and their family, at the centre. This will require services and staff to work collaboratively to achieve outcomes for each individual. It will also require a flexible philosophy and approach from services and staff.

People with disability, parents and carers felt that cultural change was necessary to realise a person centred system. Many felt that the ability of people with disability, families and carers to self manage their funds, coordinate their supports, negotiate with service providers, access mainstream supports

and directly employ support workers would be limited if the sector, services and staff do not embrace change.

There was recognition that not all service providers are at the same point in their journey to transition to a person centred approach. Many felt that some service providers were working with a person centred philosophy now, and others would need support to bring about internal cultural change.

‘There are services currently at the moment that need training to change their approach to a person centred approach. This is hard for some services.’ Parent

"Moving people with disability from one service to another can be very traumatic. We would prefer to keep our child in the service they are in at the moment so long as the service changes some of its approaches and behaviours."

Parent

Service providers suggested ways that they could be supported to bring about the culture change. More information about person centred approaches, good practice examples, encouraging dialogue and debate in the sector, individual stories from people with disability, families and carers about the positive impact of person centred approaches and change

management were identified as ways that government could help to bring about this change.

“It has to be explained what ‘Living My Way’ means and how it is going to affect people.”

Parent

Service providers identified the practical assistance they need to transition to a person centred system. This included assistance with business planning, financial modelling, transitional funding, training for board members and staff, workforce issues, information technology systems, marketing, implementing cultural change and the development of partnerships.

Many participants expressed concern that larger or better resourced service providers will have an advantage in the new system. It was felt that they will be able to manage the change better due to their ability to draw on larger financial and staff capacity. It was feared by some that smaller providers would be left behind.

“Lots of organisations have grown from small family started organisations into bigger ones, so boards may only be made up of family members. There will be a need to identify what skills will need to be recruited to help organisations transition.”

Service provider

There was strong support among participants that the government retain a role in assisting the sector develop itself to provide person centred supports and services

7. Next steps

The final stage of consultations has been completed. A separate report has been prepared on the outcomes of targeted consultations with people with intellectual disability.

The feedback obtained during the final stage of consultations and described in this report will be used to finalise the principles for creating a person centred system in NSW.

Further consultations will also occur to develop specific strategies for supporting Aboriginal people and communities to participate fully in a person centred system.

8. Glossary

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| Ability Links NSW | <p>Based on a local area coordination model, Ability Links NSW provides information, assistance and support to people with disability, families and carers to access mainstream and community based supports and services.</p> <p>Ability Links NSW places coordinators within communities to build support networks with mainstream and community based services, assist people with disability to plan for their futures and provide referral to access funded disability supports and services, as required.</p> |
| Access points | <p>Points at which a person is able to contact the disability service system - can be a physical place, person or communication channel for example, dedicated telephone line or on line access.</p> |

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| ADHC | Ageing, Disability and Home Care, NSW Department of Family and Community Services. |
| CALD | Culturally and linguistically diverse. This term refers to people from culturally and linguistically diverse backgrounds. |
| Capacity | Understanding, skills and knowledge to support and enable individuals to exercise choice and control in a person centred system. |
| Carer | <p>A carer provides care and support to someone who requires it as a result of a disability, long term or life-limiting illness, mental illness; dementia and/or aging.</p> <p>A carer is not paid directly but may receive a pension or allowance.</p> |

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| Decision support | Assistance (including sources of information and advice) available to a person with disability, their family or carers to enable them to exercise choice and control over support and service arrangements. |
| Direct payment | Funding provided directly to eligible individuals to purchase supports and services in accordance with their personal plan. |
| Disability service system | Overall system for the delivery of government funded disability supports and services in NSW. |
| DSP | Disability Support Pension |
| Early intervention | Action that seeks to reduce the impact of disability for individuals and the wider community, for example, by mitigating or alleviating the impact of a disability, and preventing a deterioration in an existing disability. |

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| Fund holder | Person or organisation that manages an individualised budget. |
| Individualised budget | Funding allocated to a person to purchase supports and services. |
| Individualised funding | A funding model through which funds are 'attached' to a person with disability and are portable. |
| Life stage approach | Person centred planning process that considers appropriate outcomes and the supports needed to achieve them for a person with disability at each stage or transition point in life. |
| Mainstream supports and services | Publically available services that are available to all citizens in NSW, for example, hospitals, general practitioner services, community health services, education, transport, sport, aged care services. |

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| National Disability Insurance Scheme (NDIS) | A proposed social insurance scheme to provide supports and services to all Australians in the event of significant disability. |
| Natural supports | Family, friends, neighbours or organisations (for example, volunteer networks) that surround and support a person. |
| Person centred approach | A way of supporting and working with people with disability that puts the person at the centre of decision making across planning, funding and support and service arrangements. |
| Personal plan | A personal plan is holistic, forward looking and outcomes based. It includes the aspirations, goals and assessed support needs of a person with disability and how these are to be achieved, including informal and formal supports. |

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| Person centred planning | A planning process that puts a person with disability at the centre of decision making about their support and service arrangements. |
| Planner | Skilled person able to assist a person with disability in a person centred planning process. |
| Support coordinator | Person or organisation that provides assistance to a person with disability to arrange, coordinate and manage supports. |

Appendix 1 – Components of a person centred system

This diagram represents a conceptual view of person centred approaches used in the consultations.

