



# LIVING LIFE MY WAY

## Putting people with a disability at the centre of decision making about their supports in NSW

Discussion paper

April 2012

This Discussion paper is available in a number of accessible formats.

- Braille
- Easy English
- Large print.

To order a printed copy of any of the above formats please contact the Person Centred Approaches Team by phone on 1800 605 489.

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## Minister's foreword

In the second half of 2011, I led an extensive series of consultations around NSW. We undertook this process to ensure that people with a disability, their families and carers have the opportunity to have their say about how we can create a person centred service system that puts them at the centre of decision making.

The twelve-month consultation process began in July 2011 with the *Living Life My Way* summit and continued with statewide consultations between August and December 2011. At the time we said that we would report back on what you had to say.

This discussion paper has been developed to provide a shared vision for a person centred system, an outline of what could change to achieve it, and a series of practical options for changing the system to deliver person centred planning, funding, services and decision supports.

The discussion paper will inform the next round of consultations which will occur across NSW during May and June 2012.

I would like to invite you to attend one of nearly 80 consultation sessions to provide feedback on the proposed policy options or to make a written or verbal submission.

We want to hear from people with a disability, their families and carers, service providers, advocacy agencies and peak bodies, government agencies and members of the community with an interest in improving disability supports.

I look forward to your participation in this important process.

**Andrew Constance**  
**Minister for Disability Services**

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# 1 Introduction

- 1 The NSW Government is exploring options for providing new ways to support people with a disability in NSW. This will involve changing the NSW disability service system to make it more person centred. A person centred service system will enable individuals, families and carers to shape and influence their support arrangements to suit their needs and their lives.
- 2 A person centred approach covers and applies to the full range of supports that may be available to a person with a disability, their family and carers. These include supports that are provided by family and friends, supports and services that are generally available in the community and specialised supports that are provided within the disability service system. Taking a broad focus is important as many people with a disability, their families and carers already meet their support needs outside the disability service system.
- 3 Person centred approaches have been implemented overseas and within Australia, including in parts of the current NSW disability services system. They have been associated with positive outcomes for people with a disability. People with a disability, their families and carers say that having greater choice and control over how resources are used gives them greater well being, independence and freedom to pursue their goals and aspirations.
- 4 People also report being able to do more with the resources they have once they are able to assume control over how the resources are used. In other words, people feel like they are able to get more out of life.
- 5 **In 2011, the NSW Government started a conversation with people who use disability supports and services and those who deliver supports and services. Between July and November 2011, we completed a round of statewide consultations with over 150 general consultation sessions attended by more than 2,400 people, the majority of whom were people with a disability, families and carers. Additional targeted consultations with Aboriginal communities, people from culturally and linguistically diverse backgrounds, people with intellectual disability were also undertaken.**
- 6 Information about the feedback, views and ideas received through these consultations is available on the Ageing, Disability and Home Care (ADHC) website [www.adhc.nsw.gov.au/about\\_us/strategies/person\\_centred\\_approach](http://www.adhc.nsw.gov.au/about_us/strategies/person_centred_approach)
- 7 When we conducted consultations in 2011, we asked participants for their views and ideas on how the system could change to be person centred. We committed to developing options for creating a person centred disability service system and undertaking further consultation in 2012 to test these options for change.

- 8 This paper provides a shared vision for a person centred system, an outline of what could change to achieve it and a series of practical options for changing the system to deliver person centred planning, funding, services and decision supports. We have consulted with the Ministerial Reference Group on Person Centred Approaches in developing this discussion paper to ensure it focuses on the right issues and asks the right questions.
- 9 The paper includes some terminology that may not be familiar to all readers. A Glossary of key terms has been included at Appendix B.
- 10 We are undertaking the final round of consultations between April and June 2012. If you would like to know more about the consultations you can visit ADHC's website or contact the Person Centred Approaches Team on 1800 605 489.

## Reform context

- 11 The NSW Government has responsibility for funding supports and services for people with a disability in NSW. The kinds of supports and services that the NSW Government funds to respond to the specific needs of people with a disability include:
  - accommodation support
  - aids and equipment
  - behaviour support
  - case management
  - day programs for school leavers and adults
  - early childhood intervention
  - employment support
  - information and advocacy
  - respite
  - therapy services
- 12 Access to disability-related supports and services is based on the needs of the person with a disability. Disability-related supports and services are different to income support (e.g. the disability support pension and carer payments) which is provided to assist with daily living expenses. Income support is the responsibility of the Australian Government and delivered through Centrelink.

- 13 The NSW Government intends to change the NSW disability service system to provide people with a disability, their families and carers, with greater choice and control over their support and service arrangements. These changes are consistent with the directions of reform to disability services nationally and internationally. Appendix A to this paper contains background information on how these changes are consistent with the intent of the United Nations Convention on the Rights of Persons with Disabilities, the National Disability Strategy and the proposed National Disability Insurance Scheme.
- 14 The proposed National Disability Insurance Scheme is particularly relevant to the changes outlined in this paper. Full implementation of the National Disability Insurance Scheme would change the way that people with a disability access supports and services and fund the unmet demand that exists in every State and Territory. The roles of State and Territory governments in planning, funding and delivering disability supports and services would also change.
- 15 At this stage, it is not clear whether the National Disability Insurance Scheme will be implemented in full, as proposed by the Commission or changed in some way.
- 16 It is important that we consider how a person centred system in NSW could work in the context of a National Disability Insurance Scheme and we have been mindful of this in developing the options for change that are outlined in this discussion paper.
- 17 While national reform directions are important for NSW, we should not delay the implementation of person centred approaches within the NSW disability service system. During the consultations we held last year most people said that NSW should move quickly to put in place person centred approaches so we can deliver better supports and services to people with a disability, their families and carers in NSW.

### **Recent changes to the NSW disability service system**

- 18 The NSW disability service system is undergoing major change, generated by significant new investment and policy reform.
- 19 NSW has moved towards the introduction of more flexible models of support and greater consumer choice over the past few years, with the trialling of self managed models and individualised funding. Some of the programs with person centred elements include Transition to Work, Community Participation, Life Choices and Active Ageing, Attendant Care and Family and Children's Programs. The experiences of people with a disability and their families and carers in taking up these new approaches are informing how the entire system can change to be more person centred.

- 20 In Stronger Together: A new direction for disability services in NSW 2006-2016, the NSW Government set out plans to increase the capacity of the disability service system by 40 per cent. In the first five-year phase of Stronger Together, this involved a record investment of \$1.3 billion (in 2006/07 dollar terms). The number of new places created during this phase exceeded projections: 29,000 places have been created compared to the target of 18,100.
- 21 On 3 December 2010 the NSW Government announced a further \$2.02 billion investment in disability services across the five years from 2011 to 2016, with a commitment to deliver 47,000 new places. This represents a 33 per cent increase in funding over the first five years and makes Stronger Together the biggest investment in disability services in NSW history.
- 22 Under Stronger Together Two there will be an increased focus on implementing person centred approaches, as well as a life stage approach to providing support that will increase certainty by building long term pathways throughout the service system.
- 23 Despite the additional investment by the NSW Government, we must acknowledge that there is insufficient funding to meet everyone's support needs and the NSW Government is not able to provide this level of funding alone. While person centred approaches will deliver significant benefits for people who are eligible for, and receive funded supports and services, it is unlikely that these changes on their own will meet everyone's needs. NSW is looking to the proposed National Disability Insurance Scheme to provide enough investment to enable the system to fully meet the needs of people with a disability in our community.
- 24 We recognise that more can be done to expand person centred approaches across the service system so that people with a disability, their families and carers have greater choice and control over their supports.

## How your views are shaping the design of a person centred disability service system

- 25 In the consultations last year, people with a disability, families and carers expressed strong support for reforms to create a person centred disability service system in NSW. There is a consensus that it is the 'right' and indeed, the only way forward.
- 26 On the basis of this feedback, this paper has been developed to inform the next round of discussions with the community. It outlines:
- a shared vision for a person centred disability service system in NSW
  - the reform directions required to achieve a person centred system
  - some options for how particular components of the disability service system would work
  - questions for you to consider and provide feedback on.

## 2 Vision for a person centred disability service system

- 27 The shared vision for a person centred disability service system in NSW is a system in which:
- individuals, families and carers are able to shape and influence support and service arrangements to suit their needs
  - 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
  - diverse and sustainable disability support providers offer quality, person centred supports and services in cost effective ways.

### What changes are required

- 28 In a person centred disability service system, a person with a disability, their family and carers are able to shape their support and service arrangements because they have access to:
- comprehensive, accurate, accessible and culturally appropriate information about the supports and services that are available
  - decision supports to enable a person to exercise choice and control where this is needed (e.g. skilled and qualified planners, financial intermediaries, support coordinators, training and capacity building)
  - individualised funding that is attached to a person rather than a program or service, providing people with clarity about the resources that are available. This enables the person to choose their supports and move between service providers if they wish. It may also include the person receiving funding as a direct or 'self managed' payment to purchase supports and services themselves
  - supports and services that can be tailored to meet their needs and preferences and which are delivered in person centred ways.

29 Figure 1 (below) illustrates what changes are required to move towards a person centred disability service system in NSW.

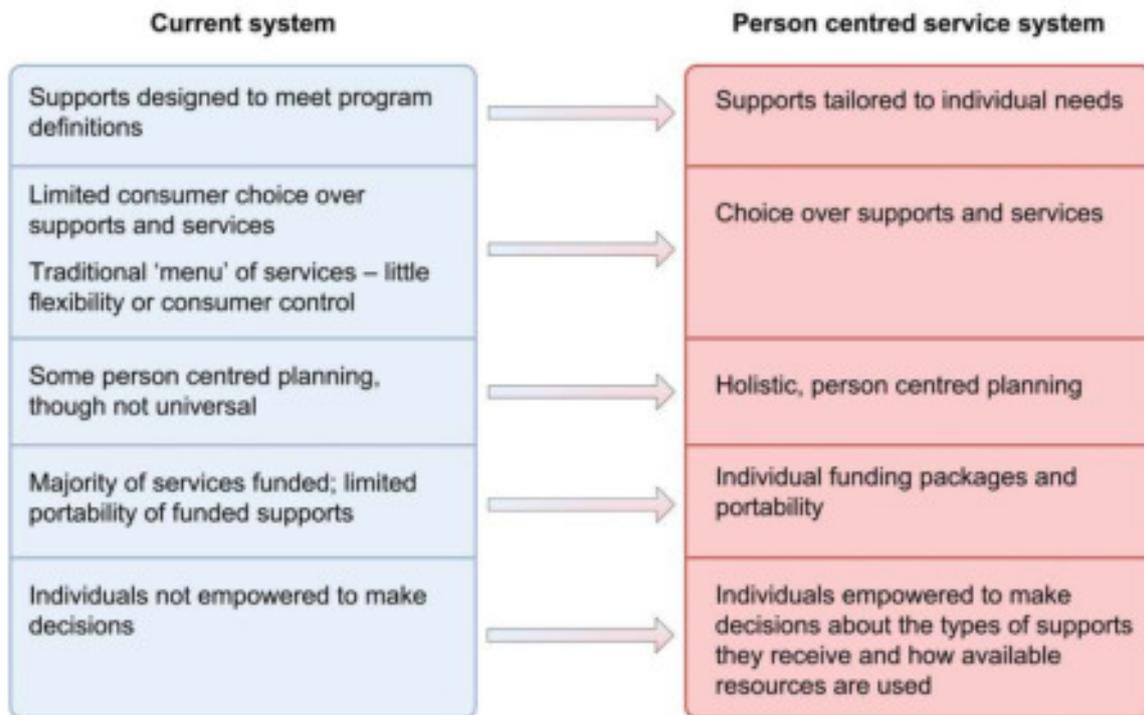


Figure 1: A shift to a person centred disability service system

### What would change for people with a disability, their families and carers?

- 30 These changes to the system give people with a disability and their families and carers the opportunity to have control and choice over how their supports are provided. Taking up these opportunities will be voluntary – it will be up to individuals to determine how much control they wish to have and how much change they wish to make to their current support and service arrangements.
- 31 We recognise that some people will want to learn more about the new arrangements and the supports that are available in order to make these kinds of decisions. They may wish to expand their skills and confidence over time, so that they can manage their own funding and coordinate their own supports. This paper discusses the types of information and decision supports that will enable people to take advantage of the choice and control that a person centred service system will offer.

### 3 Overview of a person centred disability service system

- 32 A person centred system is focused on enabling people with a disability to identify and realise their goals and aspirations. It is not designed solely around the specialist disability supports and services that the NSW Government funds. Instead, the focus is broader and is about first connecting people with supports offered in their community – through their informal supports (family, friends and others), the mainstream service system (e.g. education, public transport and health) and by other providers (e.g. family support services).
- 33 Where specialist disability supports and services are needed, these are offered in a way that provides individuals with choice and control. In order to deliver a tailored response to an individual's needs, the system must respond to the fact that not everyone is the same. The needs, capacities and willingness of individuals to exercise choice and control vary. Therefore, a range of different types of decision support and funding arrangements need to be available. Supports will also need to be flexible so that they can be tailored around individual needs.
- 34 We heard that there are distinct issues associated with Aboriginal communities that will influence the development of person centred approaches to disability supports. While Aboriginal Australians are almost twice as likely to experience disability, they have difficulty accessing appropriate supports and services and often face multiple barriers to participation.
- 35 Aboriginal people with a disability do not generally self identify as having a disability and traditional languages do not contain words that are comparable. Many Aboriginal people see “disability” as a negative label and are reluctant to use it, particularly where they experience discrimination based on their Aboriginality. In many ways, “disability” is a new conversation in many Aboriginal communities.
- 36 Within culturally and linguistically diverse (CALD) communities, there are issues that need to be considered when making the system more person centred. There are people from CALD communities who experience difficulty accessing supports and services and/or simply do not know what it is available. Negative perceptions of disability and negative experiences of government services may prevent people from CALD communities seeking supports and services. There is a need for proactive outreach to understand the needs of people with a disability from CALD backgrounds. Information and other decision supports and resources must be provided in ways that people from CALD backgrounds can access. For example, through the use of translation services and bilingual support people, outreach officers, planners and service providers.

## Decision support

- 37 We heard during the consultations that people with a disability, their families and carers may require some assistance to enable them to make well informed decisions about their supports and to achieve the best possible outcomes from their funding. This kind of assistance is often referred to as 'decision support'.
- 38 Decision support ranges from provision of accurate, accessible, comprehensive and culturally appropriate information, to periodic advice from a skilled support planner, through to more intensive and ongoing assistance with managing a person's funding and coordinating their supports.
- 39 We heard that the decision supports provided to Aboriginal people or people from CALD communities should be accessible and culturally appropriate. This includes access to interpreter services and information in community languages.
- 40 Person centred planning is a fundamental decision support in a person centred system. Some individuals, families and carers will be able to undertake their own planning without the need for any additional support – in other circumstances individuals will require support to undertake planning. We also recognise that people have differing needs and circumstances and a range of planning options and supports are needed to respond to this.
- 41 Where support is required, we envisage a system in which a skilled planner will listen to the person with a disability, facilitate a discussion around their goals and aspirations and provide information and advice about how these could be achieved. The planning process will have a broad focus, will be strengths based and explore opportunities for accessing supports that are outside the disability service system as well as the specialised supports and services that may be required. It is intended that the planning process be realistic and informed by the amount of funding that is available to an individual so that they can plan and prioritise the supports that they require.
- 42 Where a person with a disability does not require specialised disability supports, an Ability Links NSW Coordinator could undertake informal planning with the person to identify relevant mainstream and community based supports. Further discussion about the role of the Ability Links NSW Coordinators is provided at section 4.
- 43 Other decision supports that are required in the system include support coordination and fund holding (please refer to the Glossary at Appendix B for an explanation of these terms). Awareness raising and training programs are also required to support and empower individuals, families and carers to take up greater choice and control over their supports.

## Individualised funding

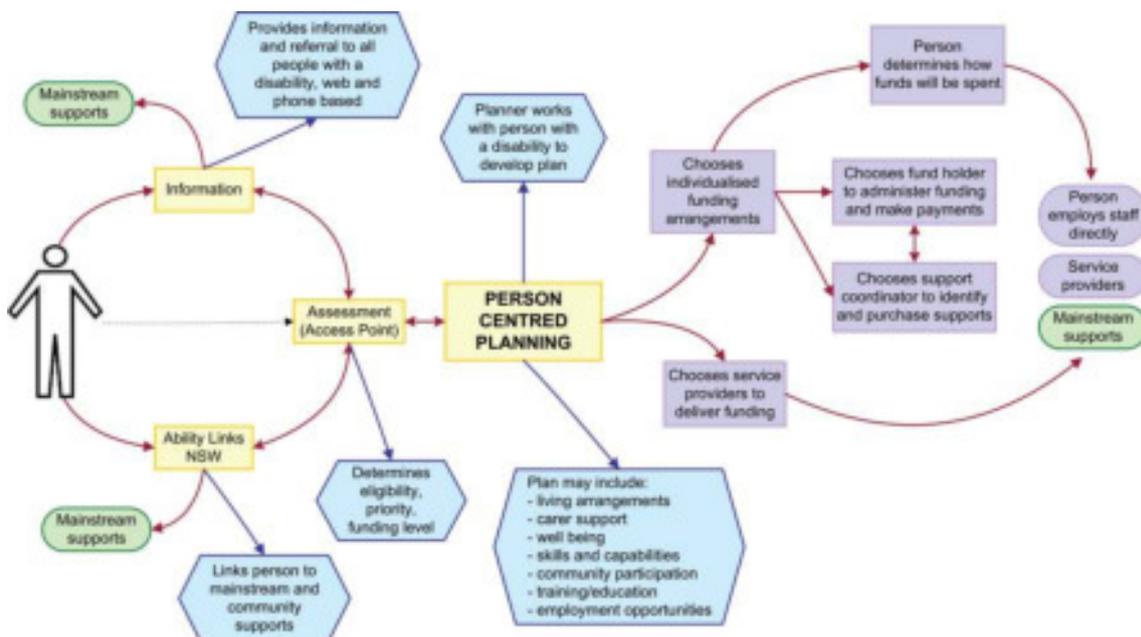
- 44 Individualised funding is a fundamental element of a person centred system. This means that funding is allocated to an individual (rather than to a program, place, support or service), and enables them to have control over what, how and when supports and services are provided. Changing funding arrangements is a powerful way of putting control in the hands of people with a disability, their families and carers.
- 45 In a person centred service system, it is proposed that people with a disability may be allocated funding on the basis of a common and consistent support needs assessment. The assessment considers their personal circumstances, aspirations and stage of life.
- 46 Individuals will then have choices over how their funding is managed. They could choose to:
- direct that their nominated service provider receives the funding for their supports from the Government (this could include a person staying with their current service provider);
  - manage their own funding; or
  - have someone else manage the funding on their behalf (a “fund holder” i.e. person or organisation that manages the financial arrangements associated with a person’s government funding allocation).
- 47 Individualised funding allows the person with a disability to choose how the funding is spent within defined boundaries, regardless of who manages the funds.
- 48 We recognise the importance of clear guidelines about what individualised funding can be spent on, including any limitations on the use of funding to ensure it achieves positive outcomes. Reasonable accountability and reporting arrangements are also required to ensure that funding is being used for the purposes that it is provided. These requirements should be clear and easy to comply with and not present a burden for people with a disability, their families and carers.

## Support for sustainable, high quality services

- 49 Finally, the disability service system cannot be person centred unless there is a strong, vibrant and sustainable service sector which offers choice of service providers and high quality supports. This will require service providers to consider offering more diverse and flexible ways of responding to people’s needs, including longer and/or more flexible hours of service.

- 50 The system changes must include strategies for supporting the disability service sector to transition to a person centred approach. Service providers will have to change the way they currently design, cost and deliver their services. They will also need to build the capacity of their staff to adopt person centred practice, while continuing to ensure the quality and safety of the supports and services that they provide.
- 51 The following sections discuss, in more detail, the options for reforms to deliver person centred planning and funding, along with the supports that people may need in order to participate.
- 52 The following diagram provides a representation of how a person centred service system might operate from the perspective of the person with a disability, their family and carers. It reflects some of the reform options outlined in the rest of the discussion paper and is included to illustrate the possible pathway in a person centred system.

Figure 2: Support pathways in a person centred system.



## 4 Supporting people to make informed choices

### Information about supports

- 53 A person centred system relies on people with a disability, their families and carers making informed choices about the types of supports and services they will use and who will provide them.
- 54 In order to make informed choices, a person with a disability, their family and carers will have to:
- understand the options that are available to them, including mainstream and disability specific supports and services
  - any relevant eligibility criteria
  - understand the results of the assessment of their needs and circumstances
  - have access to information on the price, availability and quality of a service including client feedback/experience.
- 55 In the consultations many people told us that there is a lack of accessible, reliable and accurate information about support and service options. Where information is available, it is almost impossible to determine what is relevant, the quality of the support or service and whether a support or service provides value for money.
- 56 We also heard that information and assistance will be required in different languages and in culturally appropriate formats, recognising that different communities think about and approach the provision of supports and services to people with a disability in different ways. Some examples would include access to information and material that is web accessible, downloadable applications, interactive system, and available in easy English.

### What is required

- 57 A person centred system relies on the availability of accurate and reliable sources of information about supports and services. Information needs to be provided to people with disability, their families, carers and others in different ways, including web based, telephone and face-to-face contact.
- 58 In a person centred system, anyone in an information providing role should have access to reliable information about the options available to the individual. To do this, they will require knowledge of the support and service options and strong professional networks. We also recognise that some information providers will need skills in delivering culturally and linguistically appropriate services, including the ability to use interpreting services.

- 59 Access to a source of reliable and comprehensive support and service information could be met through strategies such as a consolidated web based directory. This would be a resource for information providers so that they can deliver information through a range of means (via the internet, telephone or in person).
- 60 A directory could include:
- an easily accessible website that enables people to browse statewide, regional and local services
  - information about different support and service options, who they are relevant to and their quality, price and any eligibility criteria
  - details of people's experiences (feedback and rating) – an important means of supporting people to choose between providers.
- 61 We recognise that web based information may not be everyone's preferred form of communication, and information must be available in different formats and community languages. Access to information through personal contact (telephone or face-to-face) is equally important. The opportunities for face-to-face information exchange in a person centred system are covered below and include Ability Links NSW Coordinators, disability service system access points and person centred planning and support coordination.

### **Tell us what you think:**

- 4.1** When are the important times that you require information?  
How would you prefer to access information?
- 4.2** Key to the success of a web based information directory is the provision of feedback from people with a disability, their families and carers. How can we best capture and share individuals' experiences and views of the supports and services they use?

## Information about an individual's support history

- 62 People who are accessing disability related funding, supports and services should have access to information about their own support history, planning and funding arrangements.
- 63 One of the most consistent themes during the consultations related to the frustration experienced by many people in having to re-tell their story to different government contacts and service providers. Many people told us that they would prefer providers to be able to share some information provided by the person with a disability, on the basis of informed consent, in order to access the appropriate support and services.

### What is required

- 64 A centralised client and service management information system could be developed, containing information sourced from individuals (with appropriate consent), government agencies and non government service providers. This might include a person's support history, their support plan and funding arrangements. It would enable a person to check their arrangements and track their funding at any point in time.
- 65 Protected by privacy legislation, parts of the database could be made accessible to the providers operating the access points to the system, as well as to other service providers to reduce the number of times that individuals have to re-tell their story. Information sharing protocols would need to be developed to govern access to this information, and to ensure an individual's privacy is protected.

### Tell us what you think:

- 4.3 How do you think a centralised client and service information management system should work?
- 4.4 What kind of information do you think government and service providers ought to be able to share (on the basis of informed consent)?

## Information and access to mainstream and community based supports and services

- 66 Many people with a disability live independently and participate in study, work and general community life. They may have needs that can be met, wholly or in part, through better access to mainstream services such as health, education and community services, supports provided by family and friends or greater inclusion in the community, the economy and/or social activity.
- 67 An important feature of a person centred disability service system involves the removal of barriers that may prevent a person with a disability from accessing mainstream services or a service or activity provided in the community that would assist in meeting their needs.
- 68 In NSW we are investing in Ability Links NSW to provide information, assistance and support to people with a disability to access mainstream and community based supports and services. Ability Links NSW places coordinators within local communities to build support networks with mainstream and community based services, assist people to plan for their futures and provide referral to the disability service system, as required.
- 69 Ability Links NSW is based on a local area coordination model that has been successful in other States and Territories and countries, for example in Western Australia and Scotland. It expands on the local support coordination model currently available in some rural areas of NSW.
- 70 Ability Links NSW Coordinators will:
- provide information and assistance in accessing community and mainstream services for people who do not require specialist disability support
  - provide a locally based first point of contact for disability services
  - assist people in planning for their futures
  - proactively identify and assist people with a disability before their need reaches levels requiring specialised or intensive disability supports
  - refer people to disability service access points for detailed needs assessment in relation to disability supports and services
  - build relationships with local health services and schools to facilitate early identification of, and contact with, people with a disability who are not known to the disability service system
  - build relationships with disability employment providers
  - support individuals and families to use their natural community and family resources and to maintain and build new networks

- encourage those approved for or in receipt of low levels of support to locate and access services and supports
- assist those approved for, or in receipt of, low levels of support to use an individualised funding arrangement
- work with communities and mainstream services to support them to become more welcoming and inclusive.

## CASE STUDY<sup>1</sup>

Angela and her mother, supported by their Coordinator, told of their thoughts, fears and experiences in the lead-up to Angela moving to her own privately-rented home using a flexible family support package. Angela's mother feared Angela would not cope with independent living but knew she had to overcome that to find out if her daughter would make it. Angela's father did not support the move.

With her Coordinator supporting the family through this transition, Angela's dream to live independently has been realised and her confidence has grown. She now does most of her own cooking, washing and cleaning. Angela has also learned to use the local bus service and is engaged in making jewellery and other activities.

<sup>1</sup> ADHC is grateful to the Western Australian Disability Services Commission for permission to use this case study as presented. Source: Disability Services Commission, Disability Services Commission. Annual Report 2010-2011, September 2011, p.36 (Published at: [www.disability.wa.gov.au/dscswr/\\_assets/main/report/documents/pdf/2100\\_dsc\\_annual\\_report\\_book\\_ver\\_final\\_low\\_bom.pdf](http://www.disability.wa.gov.au/dscswr/_assets/main/report/documents/pdf/2100_dsc_annual_report_book_ver_final_low_bom.pdf))

### Tell us what you think:

**4.5** What are the best strategies for increasing the inclusion of people with a disability in the activities available in their local community?

## Streamlined access to disability supports and services

- 71 When we spoke to people with a disability and their families and carers in 2011 we heard that the current disability service system is difficult to navigate. There are no easily identifiable places for gaining access to specialist disability supports, and eligibility criteria are often unclear.

- 72 A large number of people told us that they would like:
- points of contact that are easy to find
  - consistent needs assessment processes based upon fair and transparent eligibility criteria
  - clear and simple pathways through the system – from assessment to planning, funding and support coordination.
- 73 Under the current arrangements, central access systems operate for some services (e.g. Community Participation and Attendant Care) while there are multiple access points for others (e.g. respite in some regions, advocacy, day programs and in-home support).
- There are opportunities to improve access arrangements to provide clearly identifiable points of contact and access to the disability service system (including telephone, internet and physical places to ‘walk in’ and meet face-to-face)
  - clear and fair eligibility criteria
  - consistent and transparent assessment processes.
- 74 In a person centred system, the first step for people with a disability who require supports may be contact with the Ability Links NSW Coordinators. The role of these positions includes connecting people with a disability who require specialist supports to disability service access points.
- 75 Alternatively people may approach disability service system access points directly. From a service user’s perspective, the preferred option is to establish visible access points in multiple locations operating under a common banner, so they are easy to find. These would apply common assessment tools and processes.

### Functions of the access points

- 76 An access point can provide the following core roles:
- a point of contact, information and advice
  - 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 (e.g. crisis, high/complex, medium, low) and eligibility for specialist disability supports
  - more detailed needs assessment for disability-related supports and services
  - referral to case management and/or crisis support as required.

## Screening

- 77 Screening is an initial and immediate assessment used to determine a person's eligibility for disability support and whether they require more detailed needs assessment. In a person centred system initial screening could be performed by the Ability Links NSW Coordinators and staff located within access points.
- 78 Some participants in the consultations raised concerns about the current eligibility criteria for NSW disability services. Given the funding implications of broadening eligibility criteria, this is being considered as part of the design of the National Disability Insurance Scheme. For this reason, no changes are being considered to the NSW eligibility criteria at this stage.

## Support needs assessment

- 79 For those people whose support needs cannot be met by mainstream or community based supports and services, or by their family and friends, a detailed support needs assessment follows the initial screening.
- 80 Support needs assessment in a person centred system aims to provide an appropriate response to a person's life stage and their current and future support needs. A consistent approach is required for identifying a person's needs which will involve understanding of the person's goals, aspirations and their personal circumstances.
- 81 We will need to develop assessment tools that can be used to inform and influence the assessment of disability-related support needs. This is a complex task and there is similar developmental work occurring at the national level, in relation to the National Disability Insurance Scheme.
- 82 Assessment should be conducted, or reviewed by a skilled professional and accompanied by an understanding of the likelihood of a person's eligibility to receive individualised funding. Support needs assessment combined with this understanding then informs and influences the direction of a person centred plan.

## Other functions

- 83 It is possible for the access point to provide a more comprehensive range of functions which make them more like a 'one stop shop' for people with a disability. These additional functions could include person centred planning, prioritisation and allocation of individualised funding, case management, support coordination and fund holding roles.

- 84 In allocating a broader range of functions to the access points we will carefully consider the implications for the choices available to individuals, their families and carers. We will also consider separating some functions and roles and who provides them (e.g. information, planning, service delivery, case management and fund holding). The capacity of relevant organisations to undertake a broader range of functions will also be relevant.

### **Tell us what you think:**

- 4.6** What is the best way of providing access to the disability service system?
- 4.7** What functions do you think sit best in common access points?

### **Person centred planning**

- 85 Person centred planning is intended to support people with a disability to live life their way and fulfil their potential to the greatest extent possible. People with a disability, their families and carers have told us that they strongly support the introduction of person centred planning to enable them to make informed choices about their supports. Choice and control over supports and services enables people to set goals and expectations for different stages of their life with greater confidence and certainty – as any other citizen would.

### **CASE STUDY<sup>2</sup>**

Paul is in his sixties and was diagnosed with an intellectual disability as a child.

Paul is being supported by a provider of his choice so that he can achieve his goals. In his person centred plan Paul said he wants to learn new life skills so that he can live independently in his own home and continue to participate in his local community.

Paul also said he wants to learn to read, write and do basic mathematics so he can carry out daily living skills such as reading signs, labels and exchanging money.

Paul now lives on his own in the community and works in supported employment.

Paul, who likes food, loves his job working in the kitchen at a commercial café where he clears tables, washes dishes, heats Meals on Wheels packs and prepares the fruit and vegetables. The chef at the kitchen said Paul “has never missed a day of work” and “makes everyone laugh when it gets a bit stressful”.

The local community is supportive and inclusive of people with a disability. It is hoped that with Paul’s individualised funding and a supportive environment, he will be able to continue to live life the way he wants to.

<sup>2</sup> ADHC acknowledges the case scenarios have been taken from Aiming High- New directions in day programs for adults with a disability published at [www.adhc.nsw.gov.au/\\_\\_data/assets/file/0016/234142/AimingHighArtworkpart1.pdf](http://www.adhc.nsw.gov.au/__data/assets/file/0016/234142/AimingHighArtworkpart1.pdf)

- 86 Effective person centred planning, as part of a person centred system would:
- understand a person’s disability-related support and service needs in context of their family, community and life stage
  - engage a person with a disability along with their family, carers or other support people in planning for supports and services to meet their current and future needs
  - identify informal and formal supports and services which meet needs and assist the person to achieve their goals and aspirations, with consideration of the benefits, relevance, availability, quality and cost of different support and service options and how they would be resourced
  - listen to and respect the views of the person with a disability (along with others who are involved in the planning process) in choosing between support and service options and
  - encourage and support people to determine their own support and service arrangements, including what supports they need and how they wish to coordinate them.
- 87 The following sections outline the options for delivering person centred planning in a person centred system.

### What goes into a plan

- 88 The intent of person centred planning is to identify the informal and formal supports and services that will enable a person with a disability to live life their way. At the same time, the key public policy objectives are to maximise opportunities for people with a disability to achieve their potential, participate in the economy and in their community and to ensure the proper use of public funds.

- 89 During the consultations many participants told us that person centred planning ought to consider a person's total support needs and be flexible and open to innovative ideas. Participants also said that supports and services should be directed at achieving good outcomes in terms of the person's health, safety, wellbeing and social participation.
- 90 Taking an 'outcome focused' approach to planning would consider the:
- person's needs and life stage
  - family context and the support provided by their family and friends
  - person's likes, interests, aspirations and goals
  - opportunities for community and social participation
  - opportunities for economic participation (employment).
- 91 Planning will also need to consider ways to enable the person to achieve the outcomes that they have identified. These could include access to:
- mainstream and community based supports and services
  - supports provided by family and friends
  - disability-related supports and services
  - aids and equipment
  - information and training.

92 The following diagram summarises the key areas that the planning process should consider.



Figure 3: Illustration of a person centred plan.

- 93 The Government is considering how to guide the person centred planning process to ensure it considers all these factors. Options include:
- providing information, guidance and advice during the support needs assessment and planning processes
  - using a life stage approach to guide the planning, by specifying the outcomes sought at different life stages and the types of supports that would contribute to achieving those outcomes
  - having set criteria for the components of a person centred plan that require funding or
  - approval of each person centred plan.
- 94 People with a disability and their families and carers have told us that strict funding rules and approval processes would stifle innovation and slow things down. We were asked to consider other options for balancing choice with the need to deliver good outcomes. A number of people identified that the life stage approach would be helpful to provide some guidance and direction to planning and promote long term outcomes for individuals, families and carers.
- 95 A life stage approach describes the outcomes sought at distinct life stages and outlines the types of supports and services that would support their achievement. For example, early intervention therapies in early childhood, a focus on school preparedness prior to school entry or participation in transition to work programs as a person enters adulthood. A life stage approach provides structure and opportunities to adjust supports and services at key points in a person's life.
- 96 In the consultations, we heard that that many people would appreciate more guidance about the benefits of different types of supports and services. Parents of young children with a disability, in particular, said that they require advice on therapies that are proven to be effective. This would assist parents to determine the 'right' mix of supports and services for their child. Taking a life stage approach, supported by evidence of the value and effectiveness of different services, can respond to these needs.

## Tell us what you think:

- 4.8 Do you support a life stage approach to guide person centred planning?
- 4.9 What are some of the things that should be considered in designing a life stage approach?
- 4.10 Do you think that there should be some supports that are so important that they must be included in a plan?
- 4.11 How should the life stage approach be modified to accommodate people who have adult onset of disability or degenerative conditions?

## Support to undertake planning

- 97 During the consultations, some people said that they would be able to undertake their own planning. However, most of the people that we spoke to thought it would be helpful to work with a skilled and knowledgeable planner to determine the right mix of supports and services to meet their needs.
- 98 We consistently heard that family members, carers, friends and others often play an important role in supporting a person with a disability and ought to be able to participate in planning. As people's circumstances and decision making capacities are different, planning processes will be designed to make sure that a person's choice about who participates are respected and taken into account.
- 99 In a person centred system, the role of a planner will be to facilitate discussions around the person's aspirations and goals and provide knowledge and guidance on the support and service options available. They will also provide advice to the individual on how to obtain funding for disability related supports and the best use of the funding that is allocated.
- 100 Planners should have high expectations and positive beliefs about people with a disability, a supportive attitude and be skilled in working with people with a disability. They will require strong local service knowledge and networks, with access to information on the range, availability, price and quality of services. They must also understand relevant assessment and funding processes in order to support people through the planning process and advise on support and service options.

## CASE STUDY<sup>3</sup>

Jimmy has a moderate to severe intellectual disability and mental illness and he does not stay interested in things for very long.

With the help of his coordinator Jimmy and his mother have worked out a plan which has been designed to build a strong support community around him, building on his love of people.

It was Jimmy's interest in gardening around which the plan was focused. He was attending a day program for five days a week but his mother negotiated for him to attend his day program for three days per week and on the other two days for his funding to pay for a direct support worker. This provides Jimmy with stability which he needs as well as flexibility.

Jimmy joined a community gardening group, creating a sense of belonging for him. His support worker is helping him develop his gardening skills and he is becoming friends with other group members. His garden space is now a focal point for people to get to know him and share with him.

Jimmy and his family hope to incorporate these new friends into his circle of support so they can become his natural community champions.

His plan has a long way to go but with the support from Jimmy's planner, his family has been able to plan a life for Jimmy they would never have thought possible.

<sup>3</sup> ADHC wishes to thank Jimmy and his family for sharing his plan with us

- 101 Where a planner is required, a person could source planning from a range of providers. Options include sourcing planning from:
- the points at which a person is able to contact the disability service system (eg. an Ability Links NSW Coordinator)
  - a private planner or non government organisation (funding for planning would be provided separately to the person's support funding)
  - giving people the choice about where to source a planning service e.g. either from the access point or an alternative provider.
- 102 Safeguards may be required to ensure that individuals are receiving independent advice about the full range of response options that are available. For example, we are considering whether there should be some limitations on an individual's existing service provider providing planning services. This may be required to ensure that the person receives impartial and independent advice about all of the options and supports that are available.

103 A further issue to be considered is how plans should be monitored and how to measure the outcomes that have been achieved. It is proposed that the person with a disability and their planner have the opportunity to review progress at regular intervals and that there be reasonable requirements for individuals and organisations to report back to Government on the outcomes that are being achieved from the funding provided.

**Tell us what you think:**

**4.12** What range of options should be available to support people in person centred planning?

**4.13** Should organisations involved in delivery services also be involved in person centred planning?

**4.14** What other decision support and capacity building resources will people with a disability, their families and carers need in order to identify and choose their supports?

## 5 Individualised funding arrangements

104 Individualised funding arrangements attach funding to the individual, rather than to a program, place, support or service. The funding is:

- **transparent** – an individual knows the value of the supports that they use and has information about how their chosen service provider is using those funds
- **flexible** – an individual is able to determine who they want to provide supports and services, where these are provided as well as when and how
- **portable** - an individual is able to determine who they want to purchase supports and services from and to change provider (for example, if they are dissatisfied with a provider)
- **empowering** – funding arrangements enable self management to the greatest possible extent, with support available to build a person’s skills and confidence to self manage their supports.

### CASE STUDY

Tina has a spinal cord injury, was approved for the Attendant Care Program (ACP) in 2011 and transitioned on to the Direct Funding Model (DFM) in early 2012. The main reasons for choosing the DFM were enhanced flexibility and control over service delivery times and greater involvement in the recruitment and training of care workers. Tina elected to employ her care workers directly, but also arranged for several attendant care agencies to be available in emergency situations. Tina found the initial transition to the DFM to be challenging, in terms of establishing appropriate accounting, payroll and reporting systems, and elected to use a portion of her ACP grant to engage a bookkeeper. The bookkeeper helped Tina to establish all of the systems essential to the administration of the DFM and to comply with the ongoing reporting requirements.

Tina has compared the transition to the DFM as the difference between night and day. The additional flexibility in service delivery times has enabled her to return to part-time employment and to plan quality time with her children. Being directly involved in all stages of the recruitment process and having the capacity to enter into individually negotiated employment agreements with her care workers has contributed to the long-term retention of quality staff. Tina has noticed improved health outcomes and has attributed this to the fact that her care workers are well trained and are familiar with her Care Plan. Tina has used a portion of her ACP grant to engage an Occupational Therapist to develop comprehensive Manual Handling Procedures and to provide additional training to staff.

- 105 The current funding arrangements limit the opportunities for people with a disability to choose how the funding associated with their support is allocated to service providers and how their service providers design and deliver their supports. In contrast, individualised funding gives people with a disability, their families and carers control over how resources are used. This is an important aspect of a person centred system and a powerful driver of change.
- 106 The Government has made a commitment to introduce individualised funding by 1 July 2014 for anyone using disability services who wants that option. There is a great deal to consider in terms of the detail of how it will work, but some things are clear:
- disability funding in NSW can and ought to be individualised (which means it is attached to a person, even if that person chooses to stay with their current organisation)
  - funding should be allocated and distributed on the basis of different levels of need after taking into account a person's informal and formal supports, to ensure that the system is fair
  - different options for managing funding are required which a person can choose from based on their willingness and ability to manage their own funds
  - we should continue to ensure that public funds are being used to achieve good outcomes
  - accountability and reporting requirements must be clear and simple for individuals who choose to manage their own funding allocation and for service providers who administer funds on behalf of a person with a disability.

### Allocation of funding

- 107 During the consultations most people told us that they support individualised funding to provide people with a disability, their families and carers with choice and control over the resources that are available.
- 108 A detailed approach for allocating and distributing funds is under consideration and will be determined later in 2012, following careful modelling of the implications of different options, including consideration of population and demographic trends. The views expressed during last year's consultations are informing this work. A key principle for the design of the funding arrangements is that government funding should be distributed fairly and on the basis of need.

- 109 In the consultations, people with a disability, their families and carers said that they would like the funding rules to be flexible. Individuals want to purchase supports and services on the basis that they are reasonable, related to the person's disability support needs and necessary to achieve particular outcomes and goals (such as those identified in a person centred plan).
- 110 Under this approach, individualised funding could be used to purchase a range of supports and services including assistance with daily living or to facilitate a person's community participation and social inclusion and well being. It is proposed that a person could source their supports and services from established disability support providers or other organisations outside the formal disability support system. Examples include paying for a friend to support the person with a disability when they attend mainstream recreational and sporting activities or a vocational training course.
- 111 We also heard views expressed during the consultations that some disability supports and services are more appropriately funded through a direct funding grant from the Government to a service provider.

### **Tell us what you think:**

- 5.1** Are there any disability supports and services which would be more appropriately funded through a direct funding allocation to a service provider?

### **Principles for the use of funding**

- 112 The person centred system will need to ensure that a person's support funding is used to promote good outcomes. We also recognise that there should be clear and simple guidance provided about how funds can be spent to promote the achievement of good outcomes and the proper use of public resources.
- 113 Any limitations on the use of funds will be clearly specified upfront.
- 114 Funding can only be used to purchase supports that are directly related to the person's disability and to achieve their life stage and future goals and outcomes identified in their support plan. These may include:
- Moving to independent living or continuing to live independently
  - Continuing to live within the family environment
  - Enabling family or carers to receive support so they can continue their caring role

- Having better health and well being
- Improving skills and capabilities
- Having more opportunities to go out and meet friends or attend social events
- Having more opportunities for community access and participation
- Participating in education or further training
- Improving employment opportunities

Funding cannot be used for:

- income for the person, their carer or family
- supports which have been proven to be ineffective or harmful
- purposes which put a person's support arrangements at significant risk
- purposes which place the person or another person at significant risk of harm
- supports provided by another government service or program except where included in a person's support plan to prevent their support arrangements being placed at significant risk e.g. Enable NSW
- illegal activities.

115 In the consultations, many people raised concerns about paying family members. Some people were concerned about the risk of a family becoming financially dependent on the payment and not supporting the person with a disability to achieve their goals of living independently or sourcing alternative support arrangements that fit the person's needs and aspirations. Other people raised concerns that such arrangements could increase the social isolation of some people with a disability, by limiting their contact with others in the community. Consideration is being given to whether some parameters around the payment of family members are necessary.

## Fund holding

116 In a person centred funding environment, a person or organisation will hold individualised funds. During the consultations participants told us that the system must recognise that people have varying abilities and desires to self manage their funding. The system should offer alternatives for the 'fund holder' role: ranging from the person with a disability managing their own funding; to family and/or carer to a service provider acting as fund holder; to the management of funds by another person or organisation for a fee.

117 The role of fund holder includes:

- receiving and holding funding (e.g. in a bank account) once it has been allocated by Government
- day-to-day management and administration of funds, such as maintaining accounting records, payment of invoices for different types of support
- reporting regularly to the person with a disability, their family and carers on their expenditure to date and remaining funds (e.g. through regular statements)
- completing any reconciliation and reporting requirements for Government.

118 In the person centred system it is proposed that individuals will be able to choose their fund holding arrangements. Individuals or families will have the option of being the fund holder, if they wish to and can demonstrate that they are able to do so. These individuals and families would be subject to the same accountability requirements – in terms of receipt and record keeping and reporting – as other fund holding organisations.

119 It is likely that some people will not want to be the fund holder to avoid the time and effort of managing funds. Instead, they may choose to have some ongoing relationship with a fund holding organisation that will continue to undertake administrative and reporting functions on their behalf.

## **CASE STUDY<sup>4</sup>**

Kenneth is in his thirties, has a mild intellectual disability and can experience severe anxiety at times. Kenneth wants to further develop his independent living skills.

Kenneth manages his own funding and has developed his own person centred plan with support from a planner. This has enabled Kenneth to take part in things he enjoys doing and become more independent with the support of his support worker. Kenneth has chosen to attend a community college once a week where he learns computer skills. He also takes part in four other pastimes of his choice involving fitness, action, travel or environmental education.

Kenneth's person centred plan and individualised funding has harnessed his enthusiasm for banking and postage, and given him the ability to self-manage his money and the way it is spent. Kenneth has a keen interest in managing his own finances and he enjoys getting cheques in the mail.

Each week, Kenneth collects the receipts from the various activities that he has taken part in and sends them off to his fund holder for reimbursement by cheque. Kenneth then goes to the bank to cash the cheque.

<sup>4</sup> This case study has been taken from Aiming High- New directions in day programs for adults with a disability published at [http://www.adhc.nsw.gov.au/\\_\\_data/assets/file/0016/234142/AimingHighArtworkpart1.pdf](http://www.adhc.nsw.gov.au/__data/assets/file/0016/234142/AimingHighArtworkpart1.pdf)

## Support coordination

- 120 Following the completion of the planning process and the allocation of individualised funding, people with a disability, their families and carers may require assistance in arranging and managing supports. The support coordination role includes:
- identifying, arranging and managing supports once a funding allocation has been made
  - choosing and training support and service staff
  - employing and managing personal support staff
  - managing the associated legal and administrative requirements e.g. superannuation and insurance.
- 121 The role could be undertaken by a person with a disability, their family and/or carer or a third party on their behalf. The role can be short term, occasional or ongoing.

## CASE STUDY<sup>5</sup>

Debbie is from the Wiradjuri nation, she is in her forties, has Down syndrome, a hearing impairment and some back problems. Family is very important to Debbie. She lives with her sister and spends a lot of time with her extended family.

Debbie is using her individualised funding to explore her Aboriginal heritage and to develop her artistic talent, among other skills.

A support coordinator has provided information about supports and services in the community that will assist Debbie to take part in the pursuits that interest her and suit her sociable nature. With the assistance from the coordinator, Debbie is linked into the organisations that have been briefed in how to best support Debbie.

Debbie is now working with an art teacher in several mediums and her teacher is helping her to pursue the Aboriginal tradition of dot painting.

Debbie also volunteers her time sorting and hanging second hand clothes at her local recycling centre. The work keeps her active and engaged with her local community.

Debbie appreciates that the individualised funding has given her more opportunities to enjoy life.

<sup>5</sup> This case study has been taken from Aiming High- New directions in day programs for adults with a disability published at ([http://www.adhc.nsw.gov.au/\\_\\_data/assets/file/0016/234142/AimingHighArtworkpart1.pdf](http://www.adhc.nsw.gov.au/__data/assets/file/0016/234142/AimingHighArtworkpart1.pdf))

## How would fund holding and support coordination work in practice?

- 122 The roles of fund holder and support coordinator are distinct but there is overlap. In practice we would expect that individuals and families will choose to be their own fund holder and support coordinator or use the same organisation to perform both roles on their behalf.
- 123 Approaches for how it might work include:
- A direct payment approach in which funds are transferred directly to the person with a disability who undertakes the fund holding and support coordination roles.
  - A financial intermediary approach in which the fund holding functions are performed by a non-government service provider on behalf of the person but support coordination is undertaken primarily by the person with a disability and/or their family and carers.
- 124 A service intermediary approach in which fund holding and support coordination functions are performed by one or more non-government service providers on behalf of the person. In this model, the person develops a funded support plan which is implemented by the service intermediary under their direction.

### Tell us what you think:

- 5.2** What should not be paid for from an individual's funding allocation?
- 5.3** What rules and accountabilities do you think should be applied to fund holding?
- 5.4** Are the proposed principles for the use of individualised funding reasonable? If not what should be changed or added?
- 5.5** What assistance would you need to manage your own funding and coordinate your supports?

## Building the capacity of individuals to self manage their supports

- 125 We heard strong support for changes to make the disability service system more person centred and we heard some people with a disability, family members and carers express concerns that they were unsure what the new arrangements would mean for them.
- 126 Some people with a disability, families and carers may need support to develop their skills, experience and confidence to self manage their funding and supports in a person centred service system. This type of support is known as ‘capacity building’.
- 127 For example, some people said they would like to manage their supports and services themselves but felt anxious about taking on the role of fund holder. We recognise that many people will need support to build their skills and confidence to self manage their supports and funding over time.
- 128 This support might include providing:
- guidelines and manuals about how the new arrangements can work in a range of circumstances
  - advice on how to comply with rules and regulations
  - opportunities for mentoring and participation in local support networks, in order to learn from the experiences of people with a disability who self manage their supports successfully, as well as from those who have experienced challenges managing their supports
  - a one off allocation of funding to assist a person set up arrangements to manage their funded supports
  - training courses in, for example, financial management and personal budgeting.

### Tell us what you think

- 5.6** What kinds of capacity building opportunities should be available for people with a disability and their families and carers?
- 5.7** How do we best support people to assume more control over the management of their funding and support arrangements?

## 6 Supporting system reform

- 129 The vision for a person centred service system cannot be realised unless there is a sustainable service sector which offers choice of service providers and flexible, tailored and high quality supports.
- 130 There is a high level of support amongst service providers for the implementation of person centred approaches. Many service providers are already striving to translate person centred principles into practice. However, it is clear that the reform program must include strategies for supporting the disability service sector to transition. These strategies are required to:
- build capacity for change to the way providers currently design, cost and deliver their services and to support the disability workforce to adopt person centred practice
  - put in place appropriate safeguards around the quality and safety of supports.

### Supporting the capacity of the service sector

- 131 NSW has an Industry Development Plan and an Industry Development Fund which is investing in and driving sector change, development and improvement. A key policy objective is to develop and sustain a diverse not for profit sector in NSW and it is important to acknowledge that non-government providers will require some assistance from the Government through the transition phase.
- 132 The commencement of individualised funding is a major shift for service providers. Providers will have to adjust to a new operating environment, essentially moving from a guaranteed funding stream into a less certain situation where people with a disability will engage them directly to deliver supports and bring funding with them. It may take time for providers to change their services to better match what people want from them and to establish partnerships with other service providers in the specialist system and within their local communities. Providers will also need to have staff that are well trained and skilled in delivering person centred supports.
- 133 Investment in the system to support a transition by the current service sector to a person centred system may include:
- continuation of program-based funding for certain service types or for services in low demand locations as identified through regional service planning processes
  - time limited financial assistance to transition to individualised funding
  - financial incentives to diversify or change service models
  - workforce investment and funding for capacity building activities, as identified through regional planning processes

- support to develop partnerships within the sector in order to reduce service duplication, innovate or provide more holistic service offerings
  - innovation funding to support new investments and to make better use of available resources.
- 134 The Government will be working with the sector to develop a strategy and investment plan to support the sector to change. The detail of what is included in this plan and the short term investment targets will be informed by the views expressed in the next round of community consultation.
- 135 A cohesive sector strategy will be vital to support the not for profit sector to transition to a new service environment and to be in a position to invest in designing and implementing the change to service models that is required to deliver truly person centred approaches.

### Ensuring the quality of services

- 136 The disability services sector in NSW and across Australia has been moving towards developing a consistent national quality framework to ensure that supports are delivered by disability service providers to a standard of quality that meets client and community expectations.
- 137 NSW is in the process of developing a NSW Quality Framework in partnership with the sector. The framework will be aligned with the national approach to standard setting and is intended to apply to both ADHC operated and funded services.
- 138 The key issue for the new system is whether it will be mandatory for individualised funding to be spent on supports and services that are regulated and validated under this quality framework. Options put for further consultation include:
- All funded service providers must meet the NSW disability quality standards, maintain external third party validation against the service standards and monitor and report as required in order to be registered as a quality provider.
  - Service providers of some designated, higher risk supports must meet NSW disability quality standards, maintain external third party verification against the service standards and monitor and report as required to Government. Other service providers may choose to obtain or maintain quality registration as part of their competitive service offering, and a rating tool for providing client feedback is provided to inform choice of service providers.

- All service providers may elect to obtain quality registration against the NSW Disability Standards. Information is made available to people with a disability and their families and carers regarding the registration status and a quality rating tool for providing client feedback is provided to inform choice of service providers.

139 At this stage, various options are being considered and we seek your views on the preferred way to ensure the quality of services in a person centred system.

### **Tell us what you think:**

- 6.1 What kinds of support does the service sector need to change the way services are designed and delivered?
- 6.2 How do you believe the quality of supports and services should be regulated?
- 6.3 How do we balance freedom to choose a support and service provider with ensuring the quality of the support or service?

## 7 Participating in consultation

We value your input and encourage you to provide comments and feedback on the reform directions that are proposed and outlined in this paper.

Statewide consultations will be held throughout May – June 2012 and will include group discussions with people with a disability, their families and carers and separate workshops with service providers.

Information on consultation sessions can be found on the ADHC website: [www.adhc.nsw.gov.au/about\\_us/strategies/person\\_centred\\_approach](http://www.adhc.nsw.gov.au/about_us/strategies/person_centred_approach)

### Making a submission

If you are unable to attend one of the consultation sessions, you can make a submission by:

**Online:** [www.adhc.nsw.gov.au/pca](http://www.adhc.nsw.gov.au/pca)

**Email:** [pcaconsultations@fac.s.nsw.gov.au](mailto:pcaconsultations@fac.s.nsw.gov.au)

**Post:** Manager, Person Centred Approaches  
Ageing, Disability and Home Care  
Department of Family and Community Services  
Level 5, 83 Clarence Street, Sydney NSW 2000

**Phone:** Person Centred Approaches Team on 1800 605 489

To ensure your opinion is included in the consultations, verbal and written submissions need to be received at the above address or by phone by 1 June 2012.

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

Telephone translation services are available through the national Translating and Interpreting Service on 131 450 – please quote 1800 605 489 to the operator.

# Appendix A: Discussion questions

## Section 4: Supporting people to make informed choices

- 4.1 When are the important times that you require information? How would you prefer to access information? (page 18)
- 4.2 Key to the success of a web based information directory is the provision of feedback from people with disability, their families and carers. How can we best capture and share individuals' experiences and views of the supports and services they use? (page 18)
- 4.3 How do you think a centralised client and service information management system should work? (page 19)
- 4.4 What kind of information do you think government and service providers ought to be able to share (on the basis of informed consent)? (page 19)
- 4.5 What are the best strategies for increasing the inclusion of people with a disability in the activities available in their local community? (page 21)
- 4.6 What is the best way of providing access to the disability service system? (page 24)
- 4.7 What functions do you think sit best in common access points? (page 24)
- 4.8 Do you support a life stage approach to guide person centred planning? (page 29)
- 4.9 What are some of the things that should be considered in designing a life stage approach? (page 29)
- 4.10 Do you think that there should be some supports that are so important that they must be included in a plan? (page 29)
- 4.11 How should the life stage approach be modified to accommodate people who have adult onset of disability or degenerative conditions? (page 29)
- 4.12 What range of options should be available to support people in person centred planning? (page 31)
- 4.13 Should organisations involved in delivery services also be involved in person centred planning? (page 31)
- 4.14 What other decision support and capacity building resources will people with a disability, their families and carers need in order to identify and choose their supports? (page 31)

## Section 5: Individualised funding arrangements

- 5.1 Are there any disability supports and services which would be more appropriately funded through a direct funding allocation to a service provider? (page 34)
- 5.2 What should not be paid for from an individual's funding allocation? (page 38)
- 5.3 What rules and accountabilities do you think should be applied to fund holding? (page 38)
- 5.4 Are the proposed principles for the use of individualised funding reasonable? If not what should be changed or added? (page 38)
- 5.5 What assistance would you need to manage your own funding and coordinate your supports? (page 38)
- 5.6 What kinds of capacity building opportunities should be available for people with a disability and their families and carers? (page 39)
- 5.7 How do we best support people to assume more control over the management of their funding and support arrangements? (page 39)

## Section 6: Supporting system reform

- 6.1 What kinds of support does the service sector need to change the way services are designed and delivered? (page 42)
- 6.2 How do you believe the quality of supports and services should be regulated? (page 42)
- 6.3 How do we balance freedom to choose a support and service provider with ensuring the quality of the support or service? (page 42)

# Appendix B: International and national reform directions

## International Reform Directions

Person centred approaches support the realisation of the human rights of people with a disability to participate fully in society and to direct their own lives by exercising control over the supports and services they need.

The United Nations Convention on the Rights of Persons with Disabilities was adopted in 2006. The Convention reaffirms that people with a disability enjoy the same social, economic and cultural rights as everyone and prohibits discrimination against people with disability in all areas of life.

Since its adoption, this Convention has been ratified by 111 countries, including Australia in July 2008.

Ratifying nations are obliged to promote, protect and uphold these rights, including by consulting with, and involving, people with a disability in developing and implementing legislation and policies, and in decision-making processes that concern them.

The Convention has significant implications for disability service provision. Both international and Australian governments now recognise that people with a disability should be seen as individuals and partners in service delivery with a greater degree of control over the services they receive.

## National Disability Strategy

The Australian and State and Territory Governments agreed to a National Disability Strategy in 2011. The Strategy is a ten year plan that sets out six priority areas for action to improve the lives of people with disabilities, their families and carers.

These are:

- Inclusive and accessible communities – this includes the physical environment including public transport; parks, buildings and housing; digital information and communications technologies; civic life including social, sporting, recreational and cultural life.
- Rights protection, justice and legislation – this includes legal protections such as anti-discrimination measures, complaints mechanisms, advocacy, and the electoral and justice systems.

- **Economic security** – including jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing.
- **Personal and community support** – this relates to inclusion and participation in the community, person centred care and support provided by specialist disability services and mainstream services; and care and support provided by family and friends.
- **Learning and skills** – including early childhood education and care, schools, further education, vocational education; transitions from education to employment; and life long learning.
- **Health and wellbeing** – including health services, health promotion and the interaction between health and disability service systems; wellbeing and enjoyment of life.

The reforms to make the NSW disability service system more person centred are consistent with the reform directions in the National Disability Strategy.

## National Disability Insurance Scheme

The changes to the NSW disability service system are also being considered at the same time as the possible establishment of a National Disability Insurance Scheme. A National Disability Insurance Scheme would change the way that people with a disability access supports and services across Australia.

In 2011, the Productivity Commission (the Commission) conducted an Inquiry into disability supports in Australia. The Commission provided its report Disability Care and Support to the Australian Government in July 2011.

The report described current arrangements as fragmented and inefficient. The report also identified that the system is presently under funded to meet the support needs of people with a disability, with an additional \$6.5 billion investment required each year to meet current levels of need.

The report recommended the establishment of a National Disability Insurance Scheme to fund appropriate levels of support for people with a disability. The scheme would include:

- A National Disability Insurance Scheme (NDIS), like Medicare, that would enable all Australians to access long term care and support if they have, or acquire, a significant disability.
- A National Injury Insurance Scheme, which would cover lifetime care and support needs if a person is catastrophically injured in an accident.

### Key elements of the proposed NDIS include:

- Establishment of a National Disability Insurance Agency (the Agency) to oversee the scheme.
- The Agency would be the assessor and funder of care and supports. State and Territory providers, non government organisations, disability support organisations, and private business would provide the services.
- A person with a disability would be assessed and allocated a support package tailored to their individual needs. People would then be able to choose their support providers. They could choose to self manage their funding allocation, or have a disability support organisation act as fund holder on their behalf.
- Disability support organisations would be available to assist people with a disability, and their families and carers, to get the best possible outcomes from the use of their funding allocation.

In August 2011 COAG welcomed the public release of the Productivity Commission's final report on Disability Care and Support and agreed on the need for major reform of disability services in Australia through a National Disability Insurance Scheme. COAG also agreed to develop high-level principles to guide consideration of the Productivity Commission recommendations regarding a National Disability Insurance Scheme, including for foundation reforms, funding and governance.

## Appendix C: Glossary of key terms

<b>Access points</b>	Points at which a person is able to contact the disability service system - can be a physical place, person or communication channel e.g. phone or internet.
<b>ADHC</b>	Ageing, Disability and Home Care – part of the NSW Department of Families and Community Services.
<b>Capacity</b>	Understanding, skills and knowledge to support and enable individuals to exercise choice and control in a person centred system
<b>Carer</b>	<p>A carer provides ongoing help to someone who needs it because of their disability, long term or life-limiting illness, mental illness; dementia and/or ageing.</p> <p>A carer is not paid for the care they provide, however they may receive a pension or allowance.</p>
<b>COAG</b>	Council of Australian Governments
<b>Decision support</b>	Assistance available to a person with a disability to enable them to exercise choice and control over support and service arrangements.
<b>Disability service system</b>	Overall system for the delivery of disability related supports and services in NSW.
<b>Fund holder</b>	Person or organisation that manages the financial arrangements associated with a person's government funding allocation.
<b>Government funding</b>	Services that are funded directly by Government on a place or program basis.

<b>Inclusive communities</b>	Communities that accept, value and support the participation of people with a disability.
<b>Individualised funding</b>	Based on the principle that funding is attached to the person, and the person can choose how funds are managed and supports are purchased.  Individualised funding covers a range of ways funding can be provided
<b>Life stage approach</b>	Person centred planning that considers appropriate outcomes for a person with a disability at each stage or transition point throughout their life.
<b>Mainstream services</b>	Services that are available to all citizens in NSW – examples include hospitals, general practitioner services, community health services and activities, pre-school, primary and secondary schooling, transport, housing, sport, leisure and recreation and aged care services.
<b>Ministerial Reference Group</b>	The advisory group, convened by the NSW Minister for Disability Services, comprising people with a disability, parents and advocates and service providers. The group provides advice to the Minister on the Government's policy directions for person centred service delivery.
<b>National Disability Insurance Scheme</b>	The proposed national scheme to provide insurance cover to all Australians in the event of significant disability.

<b>National Disability Insurance Agency</b>	A proposed Commonwealth Government agency which would be established to lead the design and implementation of a National Disability Insurance Scheme
<b>National Disability Strategy</b>	A ten year national plan for improving life for Australians with a disability, their families and carers.
<b>Person centred approach</b>	A way of supporting and working with people with a disability that puts the person at the centre of planning, funding and support and service arrangements.
<b>Person centred planning</b>	A planning process that puts a person with a disability at the centre of decision making about their support and service arrangements.
<b>Person with a disability</b>	For the purposes of this paper reference to a person with a disability is consistent with the definitions of target groups contained in the NSW Disability Services Act 1993.
<b>Planner</b>	Skilled professional able to assist a person with a disability in a person centred planning process.
<b>Support coordinator</b>	Person or organisation that provides assistance to a person with a disability to arrange, coordinate and manage supports and services.
<b>“We”</b>	For the purpose of this paper, ‘we’ means the NSW Government.

