



# Living life my way

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

Your ideas about disability  
services in NSW

Outcomes of statewide consultations

Easy English version



August - October 2011

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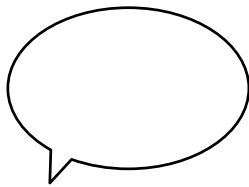
## How to use this document



This information is written in an 'easy to read' way.

We use pictures to explain some ideas.

Some words are written in **bold**. We explain what these words mean.



We've included quotes throughout this document.

The text says exactly what people told us.

We haven't written their ideas in an easy to read way.



You can ask for help to read this document.

A friend, family member or support person may be able to help you.



This Easy Read document is a summary of a longer document.



You can find the longer document on our website at **[www.adhc.nsw.gov.au/pca](http://www.adhc.nsw.gov.au/pca)**.

# Thanks for your ideas



Last year, the NSW Government started talking to people about disability services in NSW.

We held a Summit in July, where about 500 people came to talk to us.



Then, during the months of August, September and October 2011, we held meetings around the state.



There were over 170 meetings.

Lots of people came along to these meetings and shared their ideas. We talked to:



- people with disability
- families and carers
- service providers
- other groups.



We talked to people from a range of different cultural backgrounds. We spoke to people in their language. The ideas that these people shared have been included in this documents.



We also talked to:

- Aboriginal groups



- people with intellectual disability.

The ideas that these people shared have not been included in this document. We are going to write separate reports about these meetings.



Some people also wrote to us. A total of 91 people shared their ideas in writing.

Another 10 people talked to us on the phone.



This document is a summary of the things people told us they want.

This is not a final set of ideas.

We are still talking about these things. We won't be able to do everything this document says – at least not straight away.



We'd like to say thank you to everyone who shared their ideas with us.

## What we want to do



The NSW Government wants to improve the lives of people with a disability.



And we want to make the lives of families and carers easier.

We want to create services where people with a disability, their family and carers are front and centre in decision making.



We call this a **person centred** system.

It means that you have more of a say about the way you live your life.

To do this, we need to improve 3 important areas:

1. Planning
2. Funding
3. Services.

We explain how each of these areas can be improved on the following pages.

# Planning



Everyone has different needs.

Planning is the way we work out which services and supports are right for you.



A lot of people agree that person centred planning is needed in NSW.

## **What is person centred planning?**



Person centred planning is about making sure you have a say about the services and supports you use.

It puts you at the centre of planning.



This means that you will work with your service provider to create a plan. And you will have a say about everything that is in the plan.



Your family, your carers or other people that you trust can also take part if you want them to.



Person centred planning is a way of giving you more of a say about:

- the things you do
- where you go
- who works with you.

You may already be using person centred planning, or this may be something that's new for you.

“Person centred planning acknowledges the fact that disability does not mean inability because it gives the person power and control over their lives.”

*Family member of a person with disability*

### **What will be in my plan?**



We talked about the things that should go into a person's plan.



Some of the things people told us should be included are:

- personal information, like your name, age and who is in your family





- your cultural background



- the kind of support you need



- the things you like to do



- what you want to do in the future – your goals



- if you work or study



- your health



- transport and how you get around.



People talked about whether or not there should be rules about planning.



Some people don't want a set of rules.

Instead, they want the plan to depend on the needs of each person.



Some plans will be long.

Some will be short.



Some people will need more support than others.

And the type of plan will change depending on the stage of your life.

For example, imagine a girl who is 4 years old. She has an intellectual disability.

When she is young, her parents need a lot of help making sure she gets the services she needs.

But when she grows up, she and her family might not need quite as much support. She might work and live on her own.

This means that her plan will be shorter and have less information in it.



People also want to reduce the number of times they have to tell their story.

They don't want to have to do their plan again every time they move to a new service provider, or make a change in their life.

*“We’re very tired from having to tell our story again and again. My son is autistic and being asked yearly by Centrelink whether my son still has a disability is frustrating and unbelievable.”*

*Parent of a person with a disability*



Some people don't want to have a plan at all.

They still want to use the services they need.

But they don't want a rule saying that they must have a plan.



Some people said that a plan would help when families and carers are getting older.

By having a plan in place, it would help people to know that the person they care for will be ok in the future.

## Who will do the planning?



Most people agreed that the most important person in the planning process is the person with a disability.



People also suggested that the following people are involved in planning:

- families – whoever you want to include from your family. This might be:
  - parents
  - brothers and sisters
  - grandparents
  - partners
  - any other family members that you want to include.



- trusted friends



- carers



- **advocates** – these are people who provide information and advice



- **guardians** – people who are appointed by the law to make decisions with you



- medical professionals – this might include a doctor or another health professional who knows you well and can help with your plan



- your **service provider** – organisations that support people with disabilities

- any other people you would like to include.

## What support will I get?



It will be important for people with disability, their families and carers to get the support they need with planning.



Support might include:

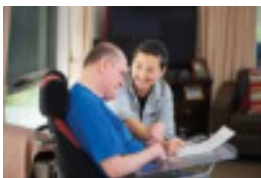
- information that is easy to read



- information in your language



- training in areas where people might need to learn more, such as:
  - managing finances
  - using computers
  - planning in general.



- help with the paperwork, or less paperwork to do.

## Would planners help?



Some people would like the help of professional planners.

These are people who will work with you to develop a plan.

People told us that they would like to be able to choose whether they have a planner or not.

People suggested that planners should be independent.

This means that they would not work for the government or for service providers.

However, not everyone agreed about this.



Everyone did agree that planners should:

- know a lot about the options for support that are available
- speak the language of the person they are supporting
- understand the person's **culture**
- understand the person's needs.

“By having a planner, we would know the direction to take and the services to obtain. With the planner’s knowledge of services and supports that exist, we can control the waiting time problem.”

*Parent of a person with a disability*

“A planner should be someone who the family trusts, who they feel comfortable with, [who is] known to the family.”

*Service provider*

### **How do we pay for planning?**



Some people were concerned that planning might cost a lot of money.

They wanted to make sure that the cost of planning did not take money away from important services.

People suggested that planning and services should be paid for separately.



# Funding



The money that the Government provides for support is often called **funding**.



The NSW Government wants to change the way that funding is provided.

We want to provide **personalised funding**.

This is a way of managing your own money for the supports that you need.

It is just for you. It is in your name.



This is a new way of doing things.

At the moment, it is usually service providers who manage the money.

“The current set up wastes funding...at the moment staff are employed to do many things I could do myself if given the right tools. For example if I have a doctor’s appointment I call a coordinator who organises staff to take me. Instead give me a taxi allowance to go myself.”

*Person with a disability*



By 2019, the NSW Government will make sure that personalised funding is available to everyone who wants it.

We want to give people the time they need to make the change to personalised funding.

### **How will personalised funding work?**



Personalised funding will give you more control over the money you receive for support.

This means that you will have more choice.



We are still talking about the way that personalised funding will work.

A lot of people shared their ideas with us. They asked questions and raised concerns.



Some people are not sure if they want to manage the money by themselves.

Some people have very high support needs and they may need others to manage the money for them.



Others are not sure about the role families should play in managing the money.

Some people may not want their family to manage their money.

Other people may appreciate the support.



Some people are worried that there will be a lot of work to do when they have to manage the money themselves.

They think there will be too much paperwork.

They are also worried that it will be hard to deal with government departments and service providers to:

- get the money
- be able to use it the way they want to.

“I want to manage my daughter’s funding and I don’t want someone telling me what to do. There needs to be an easy way to spend the funding without a lot of approvals.”

*Parent of a person with a disability*

“It’s a lot of money and I would be more comfortable if someone else could manage it, with me having control over what it can be used for.”

*Person with a disability*



There are also questions about the way the money should be paid.

For example, will it be one large sum of money every year?

Or will it be paid in small amounts every month?

All of these questions will be answered over time. We will find good solutions.

And we will support people to manage their own funding.

### **What support will I get?**



People will have different types of support, depending on their needs.

Some people will need a lot of support. Others won't need much at all.

People told us that they don't want to have to pay extra to get support managing the money. They feel that this might be unfair.

## **Will personalised funding be fair?**



We talked about the best ways to make sure that personalised funding is fair.

It's important to make sure that people get the right amount of funding for their needs.

There are different ideas about the way the government can decide on how much money people should get.



Some people suggested that the amount of money people receive should be based on their plan.

Other people said that the amount of money should be decided first.

This means that, once you know how much money you will receive, then you can make your plan.

## **What will I be able to spend the money on?**

We talked a lot about the type of things people would be able to pay for with their funding.



Everyone agreed that the money should not be spent on things like food and clothes.

They also agreed that it shouldn't be spent on things like gambling and alcohol.



However, there were a lot of things that it could be spent on, including:

- equipment and aids
- support people and carers
- activities and outings
- education
- getting help to find and keep a job.



There were different ideas about whether or not the money should be spent on housing.

Some people wanted to be able to spend the money on finding a new place to live.

Others felt that money for housing and money for support should be managed in different ways.

**“Accommodation is such a key stepping stone for a person to start living an independent life.”**

*Parent of a person with a disability*

**“We have so many problems with our son's accommodation... currently he lives in a home with old people. That is no way for a young person to live their life. He should be surrounded by people of his own age.”**

*Parent of a person with a disability*



People also talked about the high cost of providing support to people who need help 24 hours a day.

The government will decide on the best way to pay for these different types of support.

### **Will I pay more for services and supports?**

People talked about the cost of services and supports.

Some people are concerned that these things might become more expensive in the future.



Others think that having more choice will make support more affordable.

They say that service providers will compete against each other to offer good support at a reasonable price.



People who live in rural and regional areas are concerned about the cost of support.

There are not as many service providers in their area, so it's harder to make choices.

They worry that this might make prices higher.

## What paperwork will I have to do?



Everyone who receives personalised funding will have a responsibility to manage the money.

You will need to tell the government:

- how much you spend
- what you spend it on.



Some people are worried that this will mean doing a lot of paperwork. This might take a lot of time.

Some people want a lot of rules so that they know that personalised funding is fair.

Others want less rules so that they have more freedom and flexibility.

We will need to get the balance right between these ideas.



# Services

Many people go to a disability service provider if they need care and support.

Service providers offer things like:



- day programs and activities



- respite, or taking a break from your usual carer



- employment services



- housing.

## **What are person centred services?**

Person centred services are different to the way that a lot of people receive services now.

They are based on the idea that you are at the centre of the decision making.

This means that you get to decide which services are right for you.



For example, you might like to play netball with a team who train on Tuesdays at 6 pm.

In the current system, you wouldn't be able to attend this activity because most service providers offer programs from 9 am to 3pm.

With person centred services, you would be supported to attend the activity at 6 pm.

Person centred services mean that the people who work with you:



- listen to you and understand your needs



- **respect** you and treat you fairly



- pay attention to your cultural needs



- help you to achieve your goals



- help you to make choices that are right for you



- give you control.

It's important that:



- you don't have to wait to receive the services you need



- the services can change if you want or need them to – especially if your life changes



- the services are of a high quality



- the staff are professional and well-trained.

### **What will person centred services be like?**



Some people said that they don't want person centred services.

They are happy with the way things are now.

Some people are worried about making changes. This is because they worked hard for a long time to get the services they are using now.

Others are nervous that person centred services might not cover all their needs.

For example, some parents worried that if their son or daughter moved out into a private house and lived on their own, they might not:



- eat well
- look after themselves
- be safe in the community.



There are a lot of people who use person centred services already.

For example, your service provider may offer personalised planning. Personalised planning is discussed in detail on page 7.

Or, you might be part of the Community Participation program. This is one of the programs the NSW government currently offers adults with disability.

It helps people to make choices about the way they can take part in the community.

“My son is supported by a service provider to pursue his passion for fishing. He has joined a community fishing group and it gives him something to look forward to each week.”

*Parent of a person with a disability*

Sometimes, person centred services involve thinking about a problem very differently.

Instead of thinking about the way we have always dealt with problems, we might be able to come up with a new solution.

This story is a great example of a new way of thinking:

“I take care of my grandson who has a disability but I was having difficulty with day-to-day tasks of caring for him. Getting to the washing line was painful. Rather than giving me a home care service (which I would have disliked), they built me a new path to my washing line.”

*Grandparent of a person with a disability*

## Who will provide the services?

Service providers will continue to offer a wide range of services. Other services will be offered in the community.



Some examples include:

- going to the local gym
- studying at TAFE
- attending art classes at a community centre.

“Mainstream services have been out of reach but my daughter would love to have art lessons. Art therapy, music therapy... there are proven benefits from using these types of mainstream services.”

*Parent of a person with a disability*

## Will there be more choice?



Person centred services do offer people more choice. Providers to continue employing good people.



At the moment, some services are offered in the way that works best for the service provider.

Group settings are an example of this.

It is often easier for a service provider to offer services – like respite or an activity – to a group of people.



Person centred services will mean that you have more choices about the way you spend your time. And this will give you more of a say about how you live your life.

### **Will the services be good?**



Some people think that person centred services may not be as good as the services offered by service providers.

Some people think that mainstream businesses or organisations might not understand the needs of people with disability.

This might lead to issues with:

- safety
- a lack of respect for your needs.



It was suggested that a set of rules be created. These rules would be for businesses and organisations that want to offer services to people with disability.

The rules would explain:

- the way people should be treated
- the health and safety needs of people with disability.

## Who will work in person centred services?

There was a lot of discussion about the people who work with people with disability.



Some people would like their friends and family to be able to work with them.

They say this would help them to:

- get more flexible support
- pay for the support they already receive
- work with someone who really understands their needs.



Others say that having a friend or family member as a support person might be difficult.

People might argue or disagree.

Some people want to keep the way they receive support separate to their family and social lives.



Many people want to be able to choose and employ their own support people.

This will offer people a lot more flexibility and choice about who supports them.

However, it also means that people with disability and their families may be responsible for things like training carers and their working conditions.





Everyone agreed that more good people need to work in disability services.

We want people who are:

- passionate about what they do
- highly skilled
- respectful of a person's needs and their culture
- flexible and willing to change
- ready to try new things.

Attracting new workers into this area can be challenging. This is because:

- sometimes, the work is hard
- the pay is not as good compared to some other jobs, yet it is very personally rewarding.

### **How will the system be improved?**

At the moment, a lot of the systems are old and hard to use.



For example, many people with disabilities and their families find that they have to tell their story every time they work with a new area of the disability service system.

People would like this to change.



They would like to use a system that:

- shares information between services
- lets you say what information you want to share, respecting your privacy
- provides information about services providers so it is easy to choose the right service for your needs
- is easy to use and doesn't create too much paperwork.

## What do service providers think?

Service providers told us that they face a lot of challenges.

Moving to a person centred disability system will involve big changes to the way they work.

Most service providers are looking forward to making changes and offering more choices.



Others are worried about the way these changes will affect their businesses.

They are also worried that the quality of services might not be as good.

This might happen if:

- there are a lot of new providers who are not experienced in services for people with disability
- there is too much competition to make services cheaper. Cheaper services are not necessarily better.

Many believe the opposite will happen.

They say that, if service providers are more competitive, the quality of services will improve.

**“Because individual funding is brought into the open market...competition between services should improve the level of service offered.”**

*Written submission – community organisation*

Service providers also face challenges in getting and keeping good staff.

Over the next few years, service providers would like the government to help them as the system changes.

## What happens next?



Throughout the first half of 2012, the NSW Government will continue to talk to people about:

- person centred planning
- personalised funding
- person centred services.

All of the ideas, conversations and discussions will help us to create a person centred system for NSW.

## Word list



### **Advocates**

Advocates are people who support you. They help you to have a say. They also give you information and advice.



### **Culture**

Culture is a way of life. There are many different cultures in Australia and around the world. You may think or act in a certain way because of the place where you were born.



### **Funding**

Money that the Government provides for support.



### **Guardian**

A guardian is a person who acts and makes decisions for you. For example, they might look after your legal and money matters.

Sometimes, guardians are a member of your family or a friend. Or sometimes a guardian is chosen by the government.



### **Personalised funding**

Personalised funding is when people manage their own money for the supports that they need. This is also sometimes called individualised funding.



### **Person centred planning**

Person centred planning is about making sure you have a say about the services and supports you use. It puts you at the centre of planning.



### **Respect**

When you treat someone with care and understanding. You do not insult them.



### **Service providers**

Organisations that offer a range of services for people with disability.

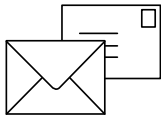
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