



# New Families - Health Professionals

## Working with health professionals

When you first receive a diagnosis of cerebral palsy you will begin the process of talking about your child's healthcare needs with professionals. It can be daunting to know which is the best service, best practitioner and best therapist for your child and family.

Many parents report that they often feel overwhelmed by the amount of research they have to do and how much information they need to absorb to make decisions about the level of intervention and support for their child. Working out what supports are available and how to work your way through the various systems with which you need to engage is also challenging. Many families who have a child with cerebral palsy may need to choose to work with a general practitioner, paediatricians, physiotherapist, occupational therapist, speech pathologist and social workers. This may be for specific needs or they may work as part of an interdisciplinary team

It is important to remember that we are all drawn to differing personalities and it is important to shop around until you find someone who suits you - with whom you feel you can develop a trusted and respectful relationship. It may be that there are particular approaches to service delivery that are important to you. Being clear about this will help you to make decisions.

The first step in determining which is the best worker or service is to do some research on what is available. Many organisations now have websites with feedback from consumers, access to blog pages and online forums. Talking with other parents is great because you can hear about their first hand experience of working with professionals.

Your local council will have a community service directory with listings of disability providers in your local community. Talking with your GP will also be a good starting point to get recommendations for whom and which service is the best to access for your specific needs.

### CP Helpline

The CP Helpline is a free confidential support and information service for anyone with questions or concerns about cerebral palsy. The Helpline provides accurate and up-to-date information about cerebral palsy and services available to people with cerebral palsy and their families. It is staffed by experienced and qualified personnel.

Tel: 1300 30 29 20, [National Relay Service](#): 133 677,

[Translating & Interpreting Service](#): 131 450

Email: [cphelpline@tscnsw.org.au](mailto:cphelpline@tscnsw.org.au)

## Family stories

### Sarah

I've been really lucky. We have five specialists and I haven't had a bad experience with them.

However, I have stood up to teachers on occasions. I didn't think I had the guts but you have to be comfortable with what they recommend as well.



February 2009

## Jonah

Definitely, question the doctors and do not sit back. Question the services. Question everything. Do lots of research, although I guess at the time it is really difficult ... Even now we are still researching ... we can't just be parents. We've got to be advocates for these kids and it's challenging.

## Tips for working with health professionals

### General tips

The following points were identified by parents as helpful in obtaining the best levels of service provision from professionals, whilst looking after their own emotional needs:

- You know your child best - trust your instincts about the services which will be the best help your child and the way that you think they should be provided.
- You have a right to full information. If you don't understand something, ask the professionals to explain it again.
- Think about your questions and write them down before you visit the service.
- Take a support person with you to help compare notes after the appointment.
- Always get copies of reports sent to you and start your own file.
- If you're not happy with a doctor or therapist look around or request another.
- Know when you have done all you can and rest.
- Don't be surprised if your GP or other mainstream health professional does not know a lot about your child's disability.

### Key philosophies

There are key philosophies of good services that can be helpful in giving parents support.

Some of these include:

- Client centred or family centred approach. Being family centred means the family (including the child) is the focus and is involved in all decisions. It is a participative and collaborative approach.
- Goal oriented focus with clear expectations - when workers work together to devise 2-3 achievable goals that are realistic, time limited and achievable it gives all participants a clear focus and prevents feeling overloaded. Talking through each of your expectations help to coordinate the service you receive.
- Strengths perspective - through the sharing of your own story you will be supported to recognize your strengths and resources you, your child and family bring to this situation.
- Work as a team to coordinate care - where you have workers who are prepared to communicate and collaborate with other professionals to prevent duplication of service and facilitate better access to services.
- Use research and evidence based practice as an underpinning to interventions. Look for a service that is interested in understanding what interventions are the most effective and successful and applying this information to its service delivery.
- Are ethical in their approach - that is, are committed to values such as non-judgemental attitudes, self determination, inclusive practice, valuing of the dignity and worth of the person and provision of services with integrity.
- Has a life span view of service delivery – that is, recognising that people with disability will experience life stage and developmental transitions where needs will require reassessment to understand what level of support is required.



## Preparing for your first meeting with a health professional

1. Do as much research about the disability, through the internet, library and read up on best practice and interventions. Write down any questions you have before the appointment.
2. Assume the health professional knows little about your particular case and take along all the information you have. That can be letters of referral, assessment information and/or medical reports. You may also want to record before the appointment your own observations of behaviours, e.g. sleeping, feeding and behaviour or medical issues, e.g. breathing regularity, seizures, mobility.
3. Establish the expectations of all involved regarding the purpose of the meeting and ascertain the length of time you will have to meet with the professional.
4. Be clear about what you want to gain from the appointment.
5. Take notes at the appointment.
6. Expect to be asked a lot of questions but also be mindful that you have a right to ask every question you have – a good practitioner will understand your need to ask questions.
7. Leave the appointment with an understanding of what further action needs to be taken by both the health professional and yourselves.

## What happens at planning meetings?

Many health providers will call a case conference or a meeting to develop a service plan with you and other health practitioners who are working together to provide support to you and your child.

This is to help decide the priorities for support services and to develop 2-3 working goals which will give all parties a clear focus on the key life/medical needs that you are targeting.

An action plan will be developed which will make clear who is responsible for what actions and interventions. A time frame will be agreed on, key workers will be identified and a review date will be set to evaluate appropriateness and effectiveness of interventions.

## What rights do I have as a consumer of disability services?

You have a right to be:

- Treated with dignity and respect.
- Involved in all decision making that is involved in the care of your child.
- Given access to all information that is written about your child until your child reaches adulthood when they then have that right.
- Given privacy and confidentiality in relation to all your personal information, except where there are issues of abuse. This means that health workers have a mandatory responsibility to report any evidence or concern in relation to child abuse and neglect to the Department of Community Services.
- Expect reasonable safety in so far as the practice and environment are concerned.

