



Building Communities of knowledge & support



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The story...



This is a story about children with CP and their families

The story...



It's a story about young people and adults with CP

The story...



A story about the professionals who provide services to people with CP and their families.

The story...

Provide information & facilitate knowledge sharing...

Mutual support

And it's a story about an **organisation**, The Spastic Centre, and our **endeavours** to provide **information** and **knowledge sharing opportunities** for these people, within a **supportive framework**.

What is CP?

- Permanent **physical condition** that affects **movement**
- Caused by **damage** to the developing **brain**, usually before birth – no cure and no pre-birth test.
- In Australia, a child is born with CP every **18 hours**
- **Complex** condition



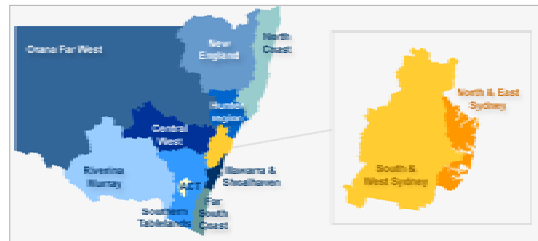
But first, a little bit about cerebral palsy...

- CP is a permanent **physical condition** that affects **movement** and **posture**.
- Caused by **damage** to the developing **brain**, usually before birth – no cure and no pre-birth test. For most, the cause remains unknown.
- In Australia, a child is born with CP every **18 hours** – approximately 12000 people with CP in NSW
- Can be very **complex** condition – people are often unable to walk or use all or some of their limbs, they can have fine motor problems, unable to communicate using speech, there can be an intellectual impairment – many people have multiple impairments.

The Spastic Centre



- Established in Mosman in 1945
- Services to people with cerebral palsy (CP)
- 3000 clients
- 800 staff
- 80 sites



- The Spastic Centre was established in Mosman in NSW in 1945 – first organisation of its kind for people with CP and their families – founded by a group of parents.
- We provide services to people with CP across NSW and the ACT – in recent years there has been a big shift in our service delivery with ten new rural sites established across NSW – prior to that we were based only in Sydney and Newcastle, with a rural outreach program.
- 3000 clients at any one time
- 800 staff
- 80 sites

Early days: parents



- In the early days, The Spastic Centre was based at just **one site**, in Mosman. All the children were **bussed** in for **treatment** and **education** at that one site.
- The organisation was very much **parent-led**. **Dads** were expected to assist with **building work** on weekends and the **mothers** were required to work **voluntarily two days** a week, helping with housekeeping duties, preparing meals and providing personal care for the children.
- Of course the **benefit** of this **close contact** between parents was that they had **frequent informal opportunities** for **mutual support** - to compare **experiences** with others who were 'in the same boat', to **share information and tips** with one another.

Now: parents



- Now, **parents** come to The Spastic Centre for **therapy** and other **services** for their **children** (or we go to them). Parents often don't **cross paths** with one another and the **informal opportunities** for **support** and **knowledge exchange** are not as readily available.

Early days: people with CP



- In the early days, children with CP were **educated** together in **special schools** and for **adults**, **employment** opportunities were limited to jobs in **sheltered workshops**.

Now: people with CP



- Now, thankfully, people with CP have **expectations** of attending **mainstream** schools, finding **employment** in the **open** market and **participating** fully in their **community**.
- That's as it should be – but one interesting **by-product** of it is a **child** with CP may be the **only** child with a disability at their **school**, **young people** may be the **only one** with CP in their TAFE or uni course, and as **adults** they may be the **only person** with a disability in their **workplace**.
- In one way, that can be very **isolating**. Many people with CP have said that there are **certain aspects** of their life that only **someone else** with CP can ever really **understand**.

Early days: staff



- In the early days, our **staff** were all **together** on **one site** – the children had to come to them (which wasn't always very convenient for the parents), but the upside was that staff could **easily share expertise** with one another.

Now: staff



- Today, staff are **distributed** at sites all over NSW. At some **rural** and regional sites, a **speech pathologist** may be the only one in that region for example, and can't easily **consult** with colleagues.
- There are now **other providers** of services to people with CP – such as **teachers** in **mainstream** childcare and schools, who also need **access** to **information** and **support** about CP.

Challenge



How to?

- offer high **quality information**
- facilitate **knowledge-sharing opportunities**

within **supportive** context (like the early days) to:

- a **diverse** range of stakeholders.



- So, our **challenge** is how to offer **information** and **knowledge-sharing opportunities**, within a **supportive** context, to such a **diverse** range of stakeholders?
- We want to not just **disseminate** high quality **information** to a **passive** audience, but **build communities of interest** so that the **participants** can take an **active** role.
- We want to make **electronic** information available as part of a **suite** of information offerings – a including parent workshops, seminars and hard copy publications.

Parents: needs



Needs

- Broad range of **information needs**
- **Quality** info
- **Current** info
- **Time** poor
- **Proactive** in informing others
- **Connect** with one another

So, taking the **needs** of these groups one by one... Parents:

- Have a **broad** range of **information needs** – want to know more about CP, latest research and treatment, services and programs available, and the ‘inside’ knowledge that only comes from other parents
- Want **high quality information** - lot of rubbish on the web (particularly generated by lawyers in the US)
- Information must be **current** – culture of immediacy
- Time poor** – need information that is easily digestible – and that is convenient to access
- Want to be **proactive** in informing others – family members, childcare workers, teachers and doctors about the special needs of their child, and what will make a difference
- Still a strong desire to **connect** with one another

Parents: solutions



E-newsletter

- Fortnightly
- Events, activities, services, programs, research.



Website

- Gateway to high quality information on CP
www.thespasticcentre.com.au
- Mutual support through stories – family listserv.



Some of the ways we've addressed these needs for parents, include:

- **Fortnightly e-newsletter** – The Scene – way of **sharing information** about upcoming events and activities, useful resources and current issues in a way that is **timely, convenient** and **succinct**. Good for me as it was a way of **disseminating** the **vast amounts of useful information** that I came across in my role as a Manager of Information Services. Become a **two-way flow**, where our subscribers are feeding in news that they come across.
- **TSC website** – our new website has an **extensive database**, which is a **gateway** to some of the **best information** on CP. On that site is also a number of fact sheets and checklists that parents can use to educate others – guides for preschool and child care staff, checklists for doctors and so on.
- Included on the website are a number of **family stories** and there has been a wonderful spin-off from that – story of Heike.

Young adults: needs



Findings

- Most in **mainstream** post-school activities
- Wanted **social contact** – but not ‘group outings’
- Need **information for transition** into adult life
- **Comfortable** in e-environment
- **Geographically** diverse
- Wanted to be ‘**heard**’

Our clients have **diverse** needs depending on the **age group**. **Beauty of e-initiatives** is that you can **tailor** them to each **audience**. We’ve found that their **needs** are **highest** around times of **transition**, and one of the key times is the **transition to adulthood**...

So, when we looked at our clients 17-30 years ... decided to conduct a series of focus groups - findings:

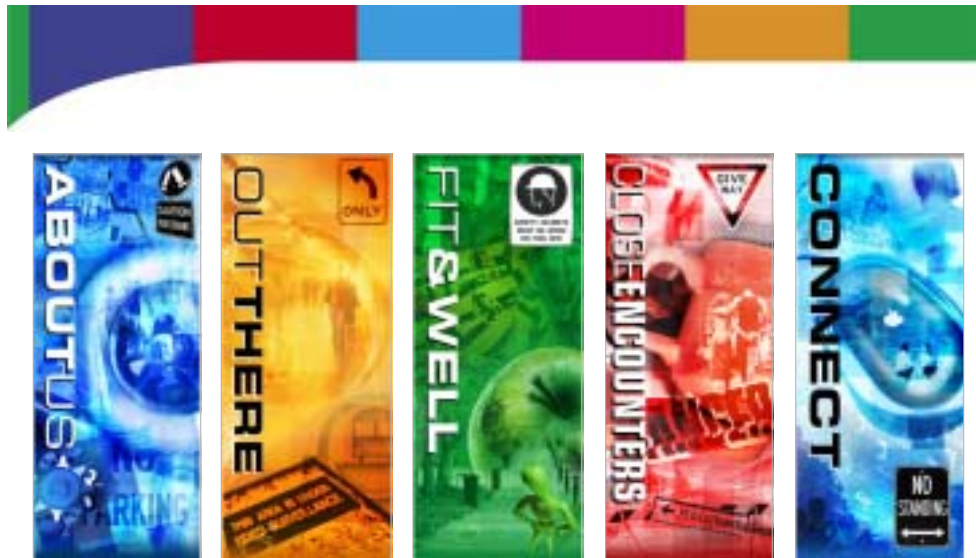
- Most were in **mainstream post-school activities** – their social networks were with people who didn’t have a disability
- Wanted to **connect** with others with CP – but not ‘group outings’
- Needed information** for transition into life as an adult
- Very comfortable** in e-environment
- Geographically** diverse
- Wanted to be ‘**heard**’ – to have a voice that is public.
- They felt a **website** would be the way to address many of these needs.

Young adults: solution



- So, through the early part of 2004, with funding from the Sony Australia Foundation, we worked with a group of 17-30 year olds to develop a website. The **site architecture** was informed by the young people and all the **content** was written by the group.

www.yconnection.org.au



- They felt that **strong imagery** was important, so we commissioned a young artist to create a series of **layered digital artwork** that reflected the **lifestyle** of this age – street scenes, cafes, uni campuses, media, etc. They also wanted to include a **disability image** in each one – **hidden**, to denote that their disability is only part of who they are – like ‘easter eggs’ in a film.
- The sense of **identity, social value** and **connection** that a website like this offers, is immeasurable. **Cameron** – moderating discussion board and updating events section.

Staff: needs



- **Staff recruitment** – particularly rural therapists
- **Professional support**
- **Information and knowledge sharing**
- **Education and information resources** for external providers

With our staff, the first issue for the organisation is actually **recruitment** – scarcity of therapists, particularly in rural areas

Then, there is a need for:

- **Professional support**
- **Information and knowledge sharing**
- **Education and information resources** for external providers

Staff: solutions



Rural recruitment site
for UK applicants

mycareer.com.au



- In 2003, we launched an **overseas recruitment drive**. We developed a **website** for **UK therapists**, backed by ads in the clinical journals in Britain. Website extolled the virtues of living in rural and regional NSW. Had a huge **impact** and the **recruitment drive** was very **successful**.
- In Australia, we now always use **mycareer.com.au** to advertise all our positions. It is much **cheaper** than newspaper advertising and **targets** the market that we're seeking.

Staff: solutions



Other initiatives

- Clinical listservs
- Intranet
- **LINCS** community/disability health co-operative (CP Helpline)



LINCS

- Other initiatives include:
- The development of **internal listservs** for our **allied health staff** – where they can share clinical practice ideas, resources, and find solutions for complex client needs.
- Comprehensive **Intranet** – now about 8 years old and we're looking to revamp it in 2006.
- Last year, we joined the **LINCS community & disability information co-operative**, which gives us access to 29,000 records of services and facilities across NSW. Used by a large number of frontline staff across the organisation, including our **CP Helpline**. The Helpline is a telephone info and support service – their biggest clients are parents and disability services.

Staff: solutions



Other initiatives

- **'Supporting People with CP'** section on our website
- **Discussion forum** for HR Managers in NGOs
- **'The Scene'** e-news



- We've also created an extensive **'Supporting People with CP'** section on our website – for our **staff** and **service providers** in other agencies
- Developed a **Discussion Forum for HR Managers in NGOs** where they can **share information** and **upload documents** for other to use as templates – such as policies and forms. This has been very well received.
- And of course staff get just as much from **'The Scene'** e-news as parents and clients.

Benefits of e-initiatives

- Greater 'reach'
- **Target market** – Gen Xs & Ys
- Greater **equity**
- Facilitated **knowledge-sharing**
- Overcome barriers of **distance** and **transport** issues
- **Cost benefits**



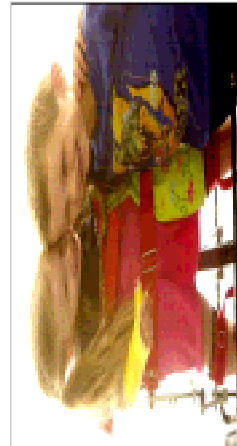
Benefits of e-initiatives -

- Greater '**reach**' – as an organisation we can reach a **far broader audience** – ultimately we want our clients and their families to **live life to the full** – and the information that is shared helps to enable this
- A good proportion of our stakeholders are **Gen Xs** or **Gen Ys** and very **comfortable in an e-environment**. For example, most parents of newly diagnosed children are Gen Xers, many of whom use the web as one of their primary sources of information
- Curiously, e-initiatives offer greater **equity** for people with CP. If you can't talk you can't participate equally in a face to face environment, but with the new special accessing devices you can use your PC to send emails, join in a discussion forum, participate in online games, find out information ... and engage in higher level activities such as online university courses.
- Facilitated **knowledge-sharing** – which benefits everyone – for our staff the clinical listservs have generated a great deal of **goodwill** between team at different regions – far more likely to engage in collaborative projects.
- Overcome **barriers of distance** – parents can jump onto a PC much easier than they can pack up the family and travel to a face-to-face information session or group. The cost of **accessible transport** is enormous and **scarce** for adults with a physical disability – particularly in rural areas.
- Organisationally, there are **huge cost benefits** for provision of information and support in this way – this has been helped by the fact that we have an **organisational commitment** to make as much of our **intellectual property** available free on the website as possible.

Psycho-social benefits



- Reduces the sense of **isolation**
- Increases **confidence**
- Provides the opportunity to find **helpful solutions** and gain a **sense of control**



Source: Shulman, Lawrence (1992), *The Skills of Helping: Individuals, Families and Groups*, 3rd ed., FE Peacock Publishers

As for the **psycho-social** benefits...

- It reduces the sense of **isolation** – for our clients, their families and our staff in remote locations – parents tell us what a difference it makes to their lives to read other people's **stories** when they are at a low point.
- It helps to increase **confidence** – for example our therapists in rural areas have all remarked on the difference it has made to their **professional confidence** having a '**brains trust**' of expertise at their disposal
- Provides the opportunity to find **helpful solutions** and gain a **sense of control** – for example there is tendency of parents of young people with CP to be **overprotective** and not encourage them to strike out on their own. With the Y Connection website, the content was written to be quite **empowering** so that the readers could find the information they need to take control of their lives.

Challenges



- **Technology** – connectivity, speed
- **Equity** – CALD and ATSI
- **Learning curve** for baby boomers
- **Moderation** of discussion boards
- **Maintenance** of websites
- **Emerging technologies**

• **Technology** – **connectivity** and **speed** for all users – conscious of people on dial-up. That was an issue for staff in our rural sites, but that has now being resolved

• **Equity** – very aware that we have to address the needs of the **CALD** and **ATSI** communities – approach their information needs in culturally appropriate ways

• **Learning curve** for **baby boomers** – for staff difficult to adjust to **sourcing** information from the **Intranet** for example – all staff now expected to have **base level competency** in using PCs and the M Office suite – educational opportunities offered to all staff – is a mindset that is hard to change.

• **Moderation of Discussion Boards** – need a moderator to set the tone and keep it on everyone's radar

• Like many organisations have a tendency to not factor in **maintenance** – ongoing issue

• We have to keep abreast of **emerging technologies** for information delivery and knowledge sharing, such as podcasts and RSS feeds. The challenge is knowing when to jump – when there is a critical mass of users that will benefit from the time and money invested.



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For The Spastic Centre, our role will always be to provide information in a supportive context to build communities of interest and engage our stakeholders so that they become active participants in the process of knowledge sharing – hopefully, we’re a good way down the track with these ideals.