



# AGSA

## THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA INC.

# NEWSLETTER

October 2009

ISSUE 88

ISSN1033-8624

FUNDED BY NSW HEALTH

## CONTENTS

### Editorial

Right to an Ordinary Life

### Contact Corner

Olivioponto cerebellar Atrophy

Common Variable Immuno  
deficiency

Charcot-Marie Tooth + Multiple  
Sclerosis

Partial Lipo Dystrophy

### Articles

BioNews

Genetic Disorders

Awareness Week



### MISSION STATEMENT

To facilitate support for  
Those affected directly or  
indirectly by genetic  
conditions throughout  
Australasia.

## EDITORIAL

We have had a couple months of adventures which all started with Genetic Awareness Week presentations by Justin Jones and James Castrisson and Peter Secomb. The talks were very inspiring and uplifting and to top it off the food and venue were excellent with views over the Surry Hills rooftops and across to Central Station. Approximately 85 people attended many of whom chatted to new people on the night.

I have just returned from presenting at the Birth Defects and Disabilities in the Developing World Conference in New Delhi India on 4- 7 October 2009 in my role as President of the International Genetic Alliance. A whole plenary session was devoted to the role of parent/patient organisations in care and prevention of genetic and congenital conditions encompassing an audience of about 180 people from all over the world. It was an excellent session and it was very well received.

There was also a morning session on support groups where Dr Kris Barlow-Stewart presented on a regional network in action: The Australasian partnership between clinical, education and peer support groups.

Jo-Anne Richards from South Africa spoke on the role of support groups and particularly the work SAIDA has done through its nurses training programme – supporting nurses in their primary care health role. It has developed a community care giver training programme, which includes counselling and psycho-social skills. Still in progress is a “plain language” textbook, being developed with the Division of Human Genetics and the March of Dimes to provide a standardized reference for medical students and doctors national. The country’s first medical geneticist qualified only in 2002. Jo-Anne has been the national chair of the Turner syndrome Contact Group of South Africa for 15 years and is deputy chair of the South African Inherited Disorders Associations. She is an internationally published author of four novels.

Martha Carvalho from the Brazilian Genetic Alliance President, International Genetic alliance Vice President, Latin America representation Brazil. spoke on cultural competency to provide quality care for families with genetic diseases.

Cynda Rushton, John Hopkins University and Children’s Center, spoke on palliative care to improve the lives of children with birth defects: The Heartsongs International Co.

Dr Pierre Mertens, Head of the International Federation for Spina Bifida and Hydrocephalus, which is the worldwide umbrella organisation

whose aim is to reduce the incidence of these conditions.

Please note the AGM is next Wednesday night so if you wish to attend please let me know.

Until Christmas time

Best wishes

**DIANNE PETRIE**

## **Right to an Ordinary Life - National Press Club**

**Hon Bill Shorten MP** *Member for Maribyrnong  
Parliamentary Secretary for Disabilities and Children's  
Services; Parliamentary Secretary for Victorian Bushfire  
Reconstruction.*

Extracts from a speech given at the National Press  
Club Canberra re **the National Disability  
Strategy**. 01/04/2009

In Australia there are approximately 1,145,000  
people with either a profound or serious disability -  
that's about the population of Adelaide.

Such a disability affects about 1 in 24 children  
aged up to 14 years. Over 50% of the 319,900  
children with disability have profound or severe  
core activity limitation.

And then there are the carers.

In 2003, approximately 2.5 million people reported  
providing informal care to a person because of  
disability or old age. This is the population of  
Adelaide, plus Perth.

500,000 were the primary carer of a person with a  
disability. This is the population of Tasmania.

Primary carers are likely to be in the poorest two  
fifths of all households and 55% receive income  
support as their main source of cash income. Most  
primary carers (71%) are women.

People with mental illness experience even higher  
rates of unemployment and lower rates of labour  
force participation than those with sensory, speech  
and physical disability.<sup>1</sup>

Poverty rates of people with disability have been  
growing, and today more than 30 per cent of  
households with a person with disability live on  
less than half the median income.

And yet they pay the highest price for the basics of  
living, for the basics of an ordinary life.

Economists believe the impact of disability  
amounts to around 30% of household income. It is  
not an exaggeration to say that 2 million  
Australians are affected every day by disability.

This is about the same as the number of Australians  
who belong to a trade union. And they're much less  
well organised. Because I'm speaking from  
experience when I say: I just wish they were as well  
organised as the union movement. I really do.

When I left the union movement and came to the  
disability portfolio in 2007 I was, like most  
Australians, not aware of the entrenched  
discrimination.

In my previous life, I had stood up for workers who  
had been injured at work, but I didn't yet understand  
the scale of the problem in Australia, or how hard it  
was for people so injured, so traumatised, so  
sidelined, so internally exiled to get the help they  
need.

I shared the same "out of sight, out of mind" attitude  
of too many other people. I was, you might say,  
colour-blind. I didn't see the intricate variety of life  
that I, as a union leader, and a Member of  
Parliament, was necessarily involved in as a  
functioning part of a democracy.

'A bugbear of everyone who loves someone who is  
disabled is that they are labelled according to their  
disability or weakness. So my son is known as  
'speech-impaired'; that is his label. Which is like  
telling someone who is totally beautiful but has big  
feet that they are primarily identified as having big  
feet and the fact that they happen also to be  
beautiful is lost. Can we focus a bit more on  
addressing the strengths so that John Smith the  
disabled boy can become John Smith the brilliant  
rocket scientist?'

Here's another from someone who became disabled  
as an adult.

'My experience changed the day I went out the first  
time with a visible impairment. I was twenty-eight-  
years-old and went to a large community event I had  
attended annually for several years. A woman  
rushed up to me and spoke to me in a tone of voice  
that one might use speaking to a very young child. I  
wondered why no-one else had ever done that in all  
the years I'd come as an able-bodied person. Surely  
it was wonderful that all of us had come?'

Most of us believe that our jobs define us, and so of  
course do the physically impaired. 13 percent of  
them have university degrees but this often doesn't  
help. 63 percent of the blind or visually impaired  
find it goes against them when they're looking for  
jobs. Those with a mental illness usually decide not  
to tell their employer.

Many found, as one said, they had to undergo 'well-  
meaning but restrictive measures under the guise of  
duty of care. No longer being allowed to drive a work  
vehicle meant the loss of a portion of my



independence, even though there were no restrictions on my driving outside of work.

'The psychological impact was that for the first time I started to feel like a disabled person, rather than as a person with a disability. Believe me, they are very different feelings.'

Access to public buildings or transport always was, and continues to be a major issue. Their access to public or government buildings matters less, because they spend so little time in them, than their access to shops and cafes and restaurants.

The people I speak of are real. They don't ask for a ramp to the top of Mt Kosciusko but they do expect to be able to get into the local public library, the local community centre.

They are in fact the last of the invisible, marginalised groups whose suffering is overlooked by the broader community.

They are more likely to be in prison.

This issue is of huge concern to me. Susan Hayes of the University of Sydney found that 20 percent of people in the prisons of New South Wales, that's eighteen hundred prisoners, had an IQ below 70, which represents a serious intellectual disability, compared with 1 to 2 percent of the general population.

And what I want to know is, what are we doing wrong that is turning them to crime. What are we doing wrong as a society to let so many people with an intellectual disability to end up in and out of the prison system?

Is it to do with their developing anti-social and aggressive behaviour, because of the way we treat them?

Maybe. Is it to do with the accommodation we put them in, which makes it hard for them to live without dignity and self-respect?

Maybe. Is it to do with our not allowing them to enter the general workforce? Absolutely, I'd say.

I've been thinking about all this, and I've come to some conclusions, and I make no apologies for seeing disability as an issue, not of resource allocation, but of basic civil rights.

I believe it is the last frontier of practical civil rights in this country. And after two and a half centuries, we may reach that frontier.

Rights remain theoretical especially for people with severe disabilities and their carers, without adequate access to robust and specialist service systems.

To take a simple example: if someone was told they could not get on a bus, train or taxi because of their sex, or their old age, or the colour of their skin, there would be an outcry.

If someone is unable to get on a bus because their wheelchair won't fit - we make no comment, we turn a blind eye.

The range of accessible public buses is around 25% to 70% - depending on where you live. Again the availability of timetable and surrounding infrastructure also varies greatly. NSW has around 700 accessible buses out of nearly 1800.

It's easy enough to rationalise in those circumstances, to find reasons why it's too hard, or too expensive for that person to be allowed on the bus.

And it's somehow also too hard to ask the question: How would I feel if that was me? If that was my mother or father or my child?

Some of you may think the person in the wheelchair should demand their rights, that it's up to them. They've got it, they own it, they should deal with it, I'm busy.

I think it's up to us, to all of us, to say: "This bus isn't moving until we're all on board."

The Disability Discrimination Act came into effect in 1992, in Paul Keating's day. Only 18 years ago. 90 years after women were first allowed the vote in this country. Only 18 years ago.

And daily the cases come in, and the Australian Human Rights Commission deal with them:

...the woman refused a job as a telemarketer because she was blind in one eye;

...the man in a wheelchair told that he could not board a return flight from Thailand on an Australian airline that left him stranded there;

...blind people told they couldn't bring seeing-eye dogs into a clean, protected place.

All of these people who till 1992 had to fend for themselves, to push alone against the unmoving barriers of ignorance and prejudice, and all of us who don't want to know, the things we half-know, and will not think on.

Compare that with the racial and sex discrimination acts signed into law in 1975 and 1984 respectively - thirty-three years ago, and twenty-four years ago.

Today this prejudice, this enduring prejudice, occupies a huge proportion of complaints received under discrimination acts. For instance, under Victoria's Equal Opportunity Act, more than 700



complaints are made per year on grounds of disability.

That is more than in any other category.

It is more than complaints about sex, race, religion, sexual orientation and political activity combined. In the Australian Human Rights Commission, half of the 998 of the total 2077 complaints that were made last year were on disability grounds. Yet these complaints seldom get media coverage.

It happens in the workplace most of all. People with disability want to work. And less than 10 per cent of people on the Disability Support Pension are in any form of paid work. And this is not acceptable.

What about how you only hear media of DSP when someone is ranting? .....In the last 16 months we have made progress...

The new National Disability Agreement with the Australian Government, States and Territories will improve and expand services The Commonwealth will provide approximately \$5.3 billion in funding over five years to the States for specialist disability services.

This significant injection of new funds will provide for more services and to achieve reform of the disability service system over the life of the new agreement. The key elements of the reform of the disability service system are:

- Early intervention and planning to ensure that clients receive the most appropriate and timely support.
- Improved measurement of unmet demand for disability services.
- Population benchmarking of disability services.
- A national workforce strategy to address attraction and retention of the disability services workforce.
- A National quality assurance system for disability services.
- National harmonisation of aids and equipment.

The reform of the disability service system should create an effective, efficient and equitable disability services system. Together these reforms will provide a responsive system of disability support that is easy to access and responds flexibly to people's changing needs. If you would like to know more about the Federal Governments Strategy go to: National Disability Strategy

[www.fahcsia.gov.au](http://www.fahcsia.gov.au)

## THE NATIONAL DISABILITY STRATEGY REPORT

ACOSS, the Australian Council of Social services, reports that the release of the Governments consultation report, ***Shut Out: The Experience of People with Disabilities and their Families, in Australia*** is welcomed as the first step to inform the National Disability Strategy and strengthen the service and support for people with disabilities.

The National Disability Strategy Consultation Report found that people with disabilities and their carers experience stigmatization and are excluded from key areas of life such as work and education. Discrimination and exclusion are daily experiences for some people with disabilities. The consultation report forms part of the National Disability Strategy, which is a key component on the Government's social inclusion agenda.

ACOSS has been advocating for better support and services for people with a disability and their carers, particularly those on low incomes. One option for review is a national disability insurance scheme (which is being debated at length by the Association for Families of Children with a Disability – AAFCD – or [www.ndis.org.au](http://www.ndis.org.au)).

*Extracts From: NCOSS News Sept 2009.*

-----oOo-----

### From Carers NSW - CHANGE TO NSW HEALTH'S TRANSPORT FOR HEALTH PROGRAM

In response to the recommendations outlined in the Inquiry into Acute Care Services in NSW Public Hospitals, NSW Health has announced it will abolish the co-contribution for pensioners and health care card holders and their carers that were a feature of the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS). From July 1, the prior travel and accommodation co-contribution costs no longer apply.

For more information, please contact Fred Foster at the Primary Health and Community Partnerships Branch on 02 9391 9837.

-----oOo-----

## Did you know...?



The Bruce Lefroy Centre for Genetic Health Research is a research unit within the Murdoch Children's Research Institute (Vic), made possible by the generosity of the Lefroy family and friends.

The Bruce Lefroy Centre studies genetic diseases of the nervous system including Friedreich ataxia, Parkinson disease, brain malformations, dystonia and Huntington disease. In addition it conducts research into genetic screening. This includes screening for reproductive risk such as for cystic fibrosis, Tay Sachs disease and thalassaemia as well as screening for conditions that can affect the health of the screened individual including haemochromatosis.

## TYPE 2 COLLAGEN CONDITIONS

In an interview with Norman Swan of the ABC's Health Report, Assoc Professor Ravi Savarirayan at the Murdoch Children's Research Institute discussed some of the research that is being done on **Stickler Syndrome and other Type 2 Collagen problems.**

Stickler syndrome is the most common cause of inherited retinal detachment. Type 2 collagen is the most important protein as it is present in the vitreous of the eye and is important for the inner ear structures, it is the lubricant and shock absorbers of our joints and it's present in the spine.

Ravi Savarirayan went on to say that several years ago M.C.R.I. started looking for a test for Stickler syndrome because there were many families around Australia with it. Fortunately MCRI were able to develop the test and they are now able to offer the test through the Children's Hospital (Victoria).

*(Extract from a radio interview 7/7/08)*

## THINGS TO CONSIDER BEFORE YOUR CHILD TURNS 16

-Ring the Centrelink call centre well in advance of your child's 16<sup>th</sup> birthday to request application forms for the Disability Support Pension (DSP), Carer Allowance (adult), Mobility Allowance and Pensioner Education Supplement.

-Request an 'Authority to be a Nominee' application form if you need to complete the application form on your child's behalf.

-Make sure you lodge the application on or before your child's 16<sup>th</sup> birthday otherwise payments cannot be backdated to this date.

-If you are applying for the DSP on the basis of blindness, allow enough time to get an ophthalmologist report and ask for the appropriate application forms well in advance.

-Be aware that separate medical reports must be completed for the DSP, Carer Allowance (Adult) and mobility Allowance, and keep copies of these reports for your own records.

-Get copies of birth certificates from the registry of Births, Deaths Marriages office in your state/territory or apply online.

-Prepare copies of your child's last three school reports, bank statements, income statements and tax file number.

-Make an appointment at your local Centrelink Office to lodge the completed forms and other documentation and allow plenty of time.

-Family members can now register to use online services to complete Centrelink business for the person/s they are a nominee for. You can also subscribe to the online letters service to view and print letters.

For more information about these entitlements visit Centrelink website: [www.centrelink.gov.au](http://www.centrelink.gov.au)

-----o0o-----

## HOME MEDICINE REVIEW

A Home Medicines Review (HMR) involves a pharmacist visiting your home to check and discuss all your medicines. The visit is organised in consultation with your GP, who receives a report afterwards. Talk to your GP or pharmacist if you want to find out more about HMR's.

*From Medicines Talk and the National Prescribing Service*

## DO YOU NEED A MEDICINES LIST?

Taking the right medicine is easier when you "get to know your medicines". Get to know them by making a medicines list, or asking your pharmacist or GP to help you make one. The list should include:

- the name of each medicine and its active ingredient
- the strength of the medicine
- what the medicine is for
- how much you should take and when you should take it
- any special instructions.



Elderly people whose first language is not English may need the list to be in their first language.

Don't forget to ask your pharmacist to update your list for you when you are given a new medicine.

The list can be ordered from the NPS website:

[www.nps.org.au/consumers](http://www.nps.org.au/consumers)

*Medicine Talk Autumn 2009.*

-----oOo-----

**Share your story to help medical research.**

---

## CONTACT CORNER

---

*AGSA will publish requests for contact and letters from people searching for families with similar experiences, from those seeking or contributing specific information as well as other resource information.*

*Anyone who wishes to reply to a request or a letter should write direct to the individual or group concerned where an address is provided. The AGSA office may be contacted for the information to be passed on in the case of anonymous requests. Privacy and anonymity will be ensured if requested.*

*While AGSA aims to facilitate contacts between families it is unable to assess the suitability of these in individual cases.*

*It should be remembered that a shared genetic condition does not mean an equally shared value system between families. Different degrees of acceptance and different mechanisms for coping will be encountered and a non-judgmental approach is recommended in establishing contact.*

AGSA has received requests for contact with others with the same condition.

**Common Variable Immuno deficiency  
Charcot-Marie Tooth + Multiple Sclerosis  
Olivopontocerebellar Atrophy  
Partial Lipo Dystrophy**

---

### BIONEWS

'Reprinted with permission from BioNews (www.bionews.org.uk)"a free web-and-email-based news service on human genetics and assisted reproduction, published by the UK charity Progress Educational Trust.

**B i o N e w s 512**

**Week 08/06/09 - 14/06/09**

- The Mail on Sunday 14/6/2009 'Ten seconds that ruined our lives: Couple whose last embryo was put in another woman tells of their agony'

**A 'Common Framework of Principles'  
for direct-to-consumer genetic tests**

07 September 2009

*By Dr Frances Flinter and Emma Burton*

Frances Flinter is Chair of the working group for the 'Common Framework of Principles' for direct-to-consumer genetic testing services, Member of the Human Genetics Commission and Consultant Clinical Geneticist, Guy's and St Thomas's NHS Foundation Trust. Emma Burton is from the Human Genetics Commission Secretariat.

Appeared in BioNews [524](#)

The UK's Human Genetics Commission (HGC), the Government's advisory body on new developments in human genetics and how they impact on individuals' lives, is seeking views on a 'Common Framework of Principles' for direct-to-consumer genetic tests. The Principles were developed by an international expert working group that was convened and supported by the HGC.

Direct-to-consumer genetic tests can significantly influence choices that may profoundly affect the lives of an individual and their family. Genetic tests that can provide information about health can heighten anxieties, leading individuals to make inappropriate requests for further tests, or alternatively encourage a complacent disregard for the effects of an unhealthy lifestyle. Other tests can also provoke anxieties, such as ancestry tests that offer fundamental information about identity and ethnicity. Yet, in the majority of countries, there is very little regulation of this steadily growing market and so the quality of service and the provision of support to accompany testing are determined by the test provider.

At an international meeting, in London in June 2008, there was agreement for the need for common guidelines that would address this gap in regulation and take account of the international market for direct-to-consumer genetic tests, with tests marketed and sold over the internet. The Principles therefore provide a high-level framework, having general applicability across all jurisdictions, to promote consistency and high standards in the provision of direct genetic testing services at an international level. The Principles will help to protect the interests of people seeking direct genetic tests and their families.

The Principles will apply to all situations where it is possible for a consumer to purchase a genetic test without a prescription by a qualified medical



professional, including tests that are ordered directly by a consumer or a non-medical intermediary acting on the consumer's behalf. As well as genetic tests for health purposes, the Principles cover 'lifestyle', nutrigenetic and ancestry tests and tests that provide information about genetic relationships.

Test providers will be encouraged to sign up to the Principles and to work within them. The Principles cover all aspects of direct-to-consumer genetic testing services, including the marketing of services, the laboratory analysis of biological samples and the level of support that the consumer should be provided with when purchasing and receiving genetic tests results. In addition, they place an expectation on the test provider to supply easily understood, accurate, appropriate and adequate information to consumers about genetics and the role of genetics, environmental factor and lifestyle choices in determine health, diseases and other genetic traits. Claims made by test providers in promotional material and on websites about the clinical validity of tests, will need to be supported by relevant evidence published in peer reviewed scientific literature and test providers will be expected not to overstate the value or significance of genetic tests.

Although it is possible to foresee certain circumstances in which the results of virtually any genetic test could cause harm to an individual, the working group drafting the Principles formed the view that the possible harms associated with the results of some tests, generally diagnostic, predictive and carrier health tests may be greater. Therefore, the Principles will expect that tests with important implications for the health of the person concerned or their family - or with potential implications for reproductive choices - will only be provided in conjunction with both pre- and post-test counselling. In addition, for any test, where the results are likely to have a significant or potentially detrimental impact on the consumer, the test provider will be expected to consider whether the test should only be provided with support by an appropriately qualified genetics health professional.

The consultation begins on 8 September 2009 and will run until 6 December 2009. The HGC would welcome responses from any person or body with an interest in genetic testing both within the UK and abroad; whether you hold an interest in the regulation of direct-to-consumer genetic tests, are a provider of tests, or are a consumer who has considered purchasing a direct genetic test, we would welcome your responses to our consultation. For a copy of the consultation document, further information about the consultation or details of how to respond please email

[PrinciplesConsultation@dh.gsi.gov.uk](mailto:PrinciplesConsultation@dh.gsi.gov.uk) or visit the Human Genetics Commission website at <http://www.hgc.gov.uk/Client/Content.asp?ContentId=816>.

#### **RELATED ARTICLES FROM THE BIONEWS ARCHIVE**

#### **SOURCES & REFERENCES**

[HGC consultation on direct-to-consumer genetic testing services](#)

---

## **A diversity of views**

**Sharon Chalmers**

*A recent study of the diverse cultural contexts in which children, their families and staff communicate within paediatric health care services has found a need for hospitals to rethink how they can provide better information, training and services.*

Children's hospitals and paediatric units have led health care systems in developing family centred and child friendly models of care. Yet health care services, including paediatric services, tend to presume that the Anglo-Australian culture is neutral or 'culture-free'. Similarly, it is also often presumed that assumptions underlying Western health care are uncritically understood by many as objective and value-free.

The result is that health care workers often believe it is incumbent upon the consumer to fit in or assimilate into Australian health culture.

#### **The report**

##### ***Are you talking to me?***

1. Is the culmination of a very successful partnership that began in 2001.
2. The first two projects examined a tertiary paediatric institution to gauge the level and quality of engagement between health professionals and children, young people and their families from culturally and linguistically diverse (CALD) backgrounds.
3. The projects' results, and an international literature review, built up an evidence base that informed, indeed drove, the large scale research project which I discuss here.

The projects highlighted that :



- existing research rarely considers the everyday cultural interactions between individual children/young people, family dynamics and the provision of health care services
- there is a lack of information relating to specific health sites within the Australian context, and
- children and young people themselves are rarely directly included as consumers in health research.

To begin to redress some of these issues, our work aimed to investigate how Australian paediatric health institutions deal with the reality of a diverse and ever-changing population and the health implications for first and second generation young people and their families from CALD backgrounds.

Employing both quantitative and qualitative methods, this project went beyond a 'checklist' approach. A 'checklist' or 'cookbook' account of cultural diversity assumes that different ethnic groups have a set of common values, beliefs and practices.

For example, that all Chinese use herbal medicines or all Muslim women wear the *hijab*. These suppositions reinforce stereotypes and can compromise the quality of health care delivery. Indeed this can lead to misinformation, inappropriate or incorrect assumptions about the quality of parenting, and communication barriers based on linguistic, cultural and religious differences which can cause stress, frustration and friction amongst parents, children and staff.

There have been several studies undertaken on adult consumers from CALD backgrounds in various health care settings in Australia and overseas, yet little is known about the impact of cultural diversity on children and young people's health outcomes.

As in adult studies, we found that health consumers from CALD backgrounds in a paediatric health setting are generally satisfied with the quality of health care provided, but this does not always translate into effective communication. The research suggested that these families were less inclined to complain or articulate their concerns and there were fewer opportunities for these families to express dissatisfaction.

All children and young people inhabit multiple cultural frameworks as part of their everyday lives. From the perspective of the young people who had chronic illnesses, normalizing their adolescence was central to their feelings of 'belonging'. As with their parents/carers, notions of belonging are

marked by diversity; diversity in terms of family and friendship experiences, popular culture, gender, location, socio-economic background, migration history and of course their specific medical condition(s).

For the young people we talked with, part of this balancing act was negotiating their way through the hospital system. This was reflected in their and some staff's constant attempts to 'bargain' their treatment, whether in terms of the amount and/or frequency of taking medications or accepting/resisting on-going care.

The definition of a consumer within children/young people's health care is obviously more complex than in adult services. The family plays a central role where they ultimately become the legal and moral authority in terms of giving consent about treatment and on-going care.

However, in the case of young people from CALD backgrounds they can be the cultural and linguistic conduits for their families and this can undermine parental authority and/or place unreasonable stress on the sick child or other siblings to take on this role.

Interpreter services are widely used but there are still significant problems in relation to access, availability and use of interpreters which compromise safety and quality of care. This includes the use of informal interpreters, sometimes the young patient themselves or siblings.

Furthermore, length of medical consultations with interpreters substantially reduced the depth, content and therefore the quality of the interaction.

The transition process from child to adult services was another significant issue for the young people and their families. The existing model of transition is premised on Western understandings of childhood, adolescence and adulthood which assume a move from family-centred to individual and independent care.

Yet, the meanings, values and practices attached to concepts such as 'childhood', 'adolescence', 'adulthood', and 'parenting' are somewhat arbitrary as well as historically and culturally specific. For example, when does childhood end and adulthood begin? Where does authority reside within the family and how does the process of decision making occur within different family structures? We found that little attention has been paid to these differences and the long-term impact on young people's health care outcomes.

Children/young people with chronic illness often have complex needs. This can be compounded for recent arrivals, particularly refugee families who find themselves socially and economically isolated.



Furthermore, CALD populations are not accurately reflected in the data collected by children's hospitals which impacts on the demographic profile of users of the hospitals as well as affecting reliable estimates of interpreter need and utilisation. For example, the research revealed data collected from Sydney Children's Hospital admissions showed that 98- 99% of children are Australian-born. Even when the 'parents' country of birth' is included, these categories would not necessarily reflect cultural heritage/background or language spoken at home.

In conclusion, there is a dynamic interplay of cultures within which paediatric health care is delivered. Therefore, a child and family centred approach needs to continuously evolve in response to emerging needs.

To engage with families from diverse backgrounds and ensure safe and effective clinical care, it is critical that hospital staff develop not only an awareness of their own cultural influences but also the skills required to communicate across cultural differences. Cultural diversity is already embedded in Australian society and shifts to meet consumer demands need to be made that reflect the reality of this population: a population that also includes all children and young people.

*Dr Sharon Chalmers is an independent scholar and research consultant. She recently left the Centre for Cultural Research, University of Western Sydney where she was a Research Fellow for several years.*

**Acknowledgements:** I would like to acknowledge the contributions of all the investigators and partners: Dr A. Rosso-Buckton, Prof I. Ang, Ms C. O'Callaghan (Centre for Cultural Research, University of Western Sydney), Prof J. Mason (Social Justice Social Change, UWS), Prof. L. White (Sydney Children's Hospital), Dr B. Lord (The Children's Hospital at Westmead), Dr J. Eastwood (South Sydney West Areas Health Service), Dr A. Perry (Multicultural Health1 Chalmers, S. & Rosso-Buckton, A.(2008). Are you talking to me? Negotiating the challenge of cultural diversity in children's health care, ARC Linkage Project (2005-2008), Centre for Cultural Research, University of Western Sydney. [http://www.uws.edu.au/centre\\_for\\_cultural\\_research/ccr/publications#3](http://www.uws.edu.au/centre_for_cultural_research/ccr/publications#3)

2 This partnership comprised Sydney Children's Hospital, Randwick, the Multicultural Health Service (South East Sydney) and the Centre for Cultural research, University of Western Sydney (UWS).

3 Chalmers, S. & Allon, F. (2002). We All Come from Somewhere: Cultural Diversity at Sydney Children's Hospital,

Multicultural Health Unit, SESAHS & Chalmers, S. (2006). Culture, Health Everyday Life, Parenting Centre for Cultural Research.



This article is from the Newsletter of Consumer Health Voices of Australia -Health Voices –March 2009.

-----o0o-----

### **GOOD WILL WEEK 20-26, SEPTEMBER, 2009**

Is it time to update or make your will? The focus of this week is to draw the attention of everyone over 18 years to the importance of having a current will.

---

## **CONFERENCES**

---

### **Australian Welfare 2009 Conference**

**17 November 2009 Canberra.**

Australian Institute of Health and Welfare's one-day conference will be addressing area as diverse as housing, homelessness, children's services, disability, aging carers and families.

This year's event features speakers such as the Reverend Tim Costello, Australian of the Year Mick Dodson, the Hon Jenny Macklin MP, and Chair of the Australian Social Inclusion Board Ms Patricia Faulkner.

This year the conference is focussed on encouraging deeper understanding of the importance of social inclusion and wellbeing, while exploring the impact of government programs and services.

More Information/registration:

Email: [conference@aihw.gov.au](mailto:conference@aihw.gov.au)

Phone: 026244 1012



## PLANNING FOR PEOPLE IN LARGE RESIDENTIAL SERVICES.

The NSW Ombudsman has made certain recommendations arising from the review of individual planning in DADHC large residential centres.

For copies of the recommendations go to:

Contact: [www.ombo.nsw.gov.au/show.asp?id=525](http://www.ombo.nsw.gov.au/show.asp?id=525)

## GENETIC AWARENESS WEEK LAUNCH



Natasha Petrie and Peter Secomb

On September 2<sup>nd</sup> we celebrated Genetic Awareness Week with a gathering at the Sebel Surry Hills in Albion Street kindly sponsored by Genzyme.

We had a really lovely evening, enhanced by the talks from our special guests, Peter Secomb, who was on the Australian soccer representative team for the Special Olympics World Summer Games Shanghai. Peter talked about his experiences in Shanghai and as a representative of Australia and his mother also told us of some of the very special experiences the family had over there.

Our second guests were James Castrission and Justin Jones who kayaked across to New Zealand, and they treated us to a very funny account of their eye-popping experiences on their record making journey in 2007.

(You can check out their story on [www.crossingtheditch.com.au](http://www.crossingtheditch.com.au))

## Our three heroes



James Castrission, Peter Secomb, Justin Jones

It was a terrific evening and it was great to see families and geneticists and management committee members all chatting away together.

The goal of Genetic Awareness week is to draw attention to genetic diseases, and we were able to attract some media attention last week thanks to Palin Communications.

There was an interview on Sky News and articles in the Illawarra Mercury, the Canberra Times and the Southern Courier with others to come in The Age and the West Australian. There were interviews on Health Matters and news items on 2GB, 2SM and on the ABC in Hobart.



Kate Dunlop, Matt Burgess, Manisha Chauhan, Umesh Chauhan

