Health care for children and young people
Health Voices

Health Voices is published three times a year. Each issue has a theme that promotes debate on issues of interest to health consumers, government and industry.

Readers are encouraged to write letters to the Editor in response to journal articles or other issues in Australian health care. Authors are encouraged to submit articles for publication.

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The Consumers Health Forum of Australia

The Consumers Health Forum of Australia Inc (CHF) is the national voice for health consumers. An independent non-government organisation, CHF represents and involves consumers in health policy and program development that helps shape Australia’s health system by representing and involving consumers in health policy and program development.

Health consumers have a unique and important perspective on health as the users and beneficiaries of health care and, ultimately, those who pay for it. CHF takes consumers’ views to government and policy makers, providing an important balance to the views of health care professionals, service providers and industry to achieve a health system that reflects the needs of all stakeholders.

Current priorities include safety and quality in health care, safe and appropriate use of medicines and health care for people with chronic conditions. CHF facilitates the appointment of consumer representatives on 200 national health-related committees.

CHF believes all consumers should receive affordable, safe, good quality health care at the time they need it. The best outcomes are achieved when consumers are involved in decisions about and management of their own health care. Consumers should receive health care information when they need it in a form they can understand.

Established in 1987, CHF seeks external funding for priority projects and receives funding from the Australian Government Department of Health and Ageing and membership fees.

With its ability to access a variety of health consumer networks and extensive knowledge of consumer issues, CHF is a respected and influential contributor to the Australian health debate.

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Health care in the best interests of children

This issue of Health Voices gives voice to a small smattering of the health issues that face children and young people. It raises the question of what consumers can do to ensure that health care is in the best interests of the child or young person requiring it. The issues arise across the whole life spectrum, from the need for a better understanding of why 30% of stillbirths are still unexplained, to a better community understanding that palliative care services can help improve the quality of life for children even while there is still hope of recovery.

From how we need to improve the diagnosis of mental health problems, to how we can better communicate with people from culturally and linguistically diverse backgrounds in a hospital situation. From how integrated models are reaching homeless young people, community groups are working with parents to improve their children’s nutrition, and young people are setting up support groups for other young people.

We need to ensure that young people and parents are heard. All health professionals must recognise young people have an insight into their own health, and include them as part of their health care team. The same applies to the parents of children, particularly those children with major disabilities or chronic conditions.

The perspectives of children and young people must also be heard by government, not only in the current reforms, but across the whole spectrum of health policy and programs. An inspiring story is that of Sarah Cullen, 25, who had strokes at the age of 14 and 16 and has gone on to form Different Strokes, a health consumer organisation that provides support for young people who have had strokes, and who is also an active consumer representative through the Greater Metropolitan Clinical Taskforce (see page 3).

CHF is committed to improving health care for all Australians by giving them a voice at the national level. While we have a number of member organisations representing children, we would like to encourage more organisations that represent young people to join CHF and share their experiences of the health system so we can better inform the national debate and shape health in Australia.

Penny Gibson
Editor

Maternity services review increases options for consumers

Penny Gibson

CHF has welcomed the Commonwealth Government review into Australia’s maternity services, part of the development of a National Maternity Services Plan.

Overall, the recommendations reflect CHF principles that the health system be more people-centred, more flexible in the use of the health workforce, and more supportive of team-based care.

The review said teams of professionals must be available and affordable, particularly for more complex births or particular types of care. It recommended developing new national cross-professional guidelines to support collaborative multidisciplinary care.

Recommendations that include better utilising midwives and giving them prescribing rights and access to Medicare rebates when they work as part of a multi-disciplinary team with obstetricians and GPs are welcome. Where midwives work in collaborative settings, the government should consider support for professional indemnity insurance.

The review acknowledged that rural and remote families experience higher rates of maternal deaths and neonatal deaths and the ‘unacceptable’ gap between Indigenous and non-Indigenous Australians and recommended providing increased support for the maternity workforce, particularly in rural Australia.

Other major recommendations suggested improving data collection and analysis and research and a single integrated pregnancy-related telephone support line. While the report considered Commonwealth funding for homebirths it did not recommend it.

Of more than 900 written submissions received from individuals, organisations, professional bodies, academics and industry groups, 400 were received from individual women, many of whom had homebirthed.

Consumer representatives Leslie Arnott, Stephanie Newell, Darlene Cox,
Debbie Slater and Erika Munton attended different consultation sessions as part of the review. Some of their responses to the review are presented below.

Recognition of women
In the review foreword, Commonwealth Chief Nurse and Midwifery Officer Rosemary Bryant, said:

_This Review has made it even clearer to me that pregnancy, birthing and early parenthood are profoundly important life experiences…the birth itself and the postnatal period are for many women and their families infused with deep spiritual and/or cultural experience._

...(women’s)...motivation to engage ...(with the review process)...was often based on dissatisfaction with the current system and the choices that were or were not available to them.

The consumer representatives felt the review reflected an understanding of the needs of women as consumers in maternity services.

However, Leslie Arnott said the review needed to show more recognition of women’s input.

‘The words ‘woman’ and/or ‘women’ should appear far more throughout the document to convey what the recommendations are truly trying to say—that woman-centred care needs to be at the heart of improving maternity service care provision if we are, as a nation, able to affect meaningful changes for birthing women and their families,’ she said.

Darlene Cox said the report recognised the importance of information and support for women.

‘Without good information, women do not have options. The report does not refer to “health literacy” as such but the concept is embedded in the recommendations. The report acknowledges the critical role reliable information plays in assisting women to make decisions about their maternity care,’ she said.

‘This is consistent with the Interim Report of the National Health and Hospitals Reform Commission which emphasises the importance of health literacy.’

Worthy recommendations
The recommendations are comprehensive and, if implemented, will go a long way to address the needs of many. Recommendations are made in the key areas of safety and quality, access to a range of models of care, inequality of outcomes and access, information and support for women and their families, the maternity workforce and financing arrangements.

Ms Arnott said they were ‘poignant, required and essential to the longevity and sustainability of high quality maternity services’.

Ms Slater said several recommendations had the possibilities to make things better for consumers of maternity services and would provide information to allow women to make informed, up-to-date decisions.

For example, the development of comprehensive national data on maternal perinatal mortality and morbidity and the commitment to targeted research around interventions, and particularly caesarean sections.

‘The test will be not only in the collection of the data, but in the dissemination of the information to make this data publicly available to women in a way that is easily understood,’ she said.

‘The development of national multidisciplinary guidelines should give confidence to women that their care is in accordance with agreed guidelines, providing that they are developed by all professions and are evidence-based. The recommendation that these guidelines be developed in consultation with consumers is to be welcomed.

A number of the recommendations are directed to the needs of women in rural and remote Australia, and women from Indigenous and linguistically and culturally diverse backgrounds. This has long been overdue.

She also welcomed the recommendations that consideration be given to: the demand for, and availability of, a range of models of care; support for initiatives to improve the initiation and continuation of breastfeeding; and provision of consistent and good information for women, including setting up a single, integrated pregnancy-related telephone support line and the need to improve the availability of information and resources.

Ms Slater said recommendations relating to the training, and skilling of maternity services workforce should provide consumers with confidence.

Homebirth
Two of the consumer representatives expressed disappointment that the review did not commit to Commonwealth funding for homebirth.

Debbie Slater said a lack of funding had the potential to reduce choice for the 1% of women wishing to homebirth.

Leslie Arnott said the review acknowledged that homebirthing was a sensitive and controversial issue and the relationship between maternity healthcare professionals did not support homebirth as a mainstream Commonwealth-funded option in the short term. The review said moving to a mainstream private model of care incorporating homebirthing risked polarising the professions.
"It is clearly based on the needs, opinions and fears of clinicians rather than the needs of women...We need to create a national homebirth framework now," Ms Arnott said.

The argument that so few women choose homebirth is not logical. It only takes one death as a result of non-attendance at a homebirth to invalidate this argument.'  

Professional indemnity
Debbie Slater said the lack of professional indemnity insurance for midwives who practice privately meant that women retaining the services of a privately-practicing midwife did so knowing their midwife had no professional indemnity insurance.

The report recommends the Commonwealth support this insurance for midwives working within a collaborative, team-based model, but it is not clear whether this will include privately-practicing midwives.

"If it does not, this may mean that, when national accreditation and registration of midwives comes into effect in 2010 that privately practicing midwives will not be able to register (as registration will be incumbent on having PI cover). This means that women will not be able to legally retain the services of a privately-practicing midwife' Ms Slater said.

Breast feeding and screening
Darlene Cox said the review did not adequately address breastfeeding or screening.

'I would have liked to see increased support for breastfeeding and targets for numbers of public and private hospitals taking up the Baby Friendly Hospital Initiative. This would include support for partnerships with NGOs and small community based orgs for lactation support, such as the Australian Breastfeeding Association,' she said.

"The review also does not approach the appropriateness of screening; for example, the rate of amniocentesis in older mothers, and other interventions such as membrane rupture for overdue babies.

Conclusion
The review will feed into the National Maternity Plan that government is preparing.

Ms Arnott said it was important for consumers to continue to have meaningful and significant input into the development of the plan.

"If we can keep mothers and babies at the forefront of our decision-making processes, we will succeed in creating a better maternity care system, a better community, a better environment in which mothers can birth their babies,' Ms Arnott said.

CHF thanks the consumer representatives for their contribution to the roundtables and this article. Their views are not necessarily those of CHF.

Creating Different Strokes
Sarah Cullen

Sarah Cullen is a young consumer representative who established a health consumer organisation to support other young stroke survivors. She talks about how and why she started Different Strokes.

My life changed drastically on 9 October 1998, when a haemorrhagic stroke turned my world upside down at the age of 14. It left me having to re-learn such basic skills as walking, talking and thinking ‘normally’.

My case manager put me in touch with a young woman who had suffered a similar stroke at age 13, but 10 years earlier. Edwina and her family became a source of advice and inspiration for me and mine.

As a consequence of my experiences with that stroke and a subsequent stroke at 16, members of my rehab team identified me as a potential candidate for a position on the Stroke Network of the Greater Metropolitan Clinical Taskforce (GMCT) and Institute of Clinical Networks (ICN) as a consumer advisor and member of the executive. This led to a position on the executive of the Transition Network as, at the time, I had only recently been fully discharged from children’s services and was beginning my outpatients’ journey with the adult system.

I have learnt a great deal during my involvement with GMCT, not just about the intrinsic workings of the health system but also about the power we, as consumers, can wield to see changes suggested and implemented.

While I have the utmost respect for the clinicians I have met through my involvement on these committees, I have also seen the necessity of involving the consumer. We represent another level of ‘specialised’

Sarah Cullen receives the Young Community Contribution Award of the 2008 National Disability Awards from the Minister for Families, Housing, Indigenous and Community Affairs, the Hon. Jenny Macklin, and the Parliamentary Secretary for Disabilities and Children’s Services. Hon Bill Shorten MP.
knowledge that exists in the broader community and can point out the seemingly obvious concerns of the 'average Joe' which may otherwise be overlooked in favour of creating a system that runs as economically efficiently as possible.

It is very gratifying as a consumer representative to be treated as of equal value to the very learned around me, that my opinions and expertise are as much value as anyone else's at GMCT. I am listened to and respected.

**Different Strokes**

At the launch of Stroke Week in September 2007, the Executive Director of the Stroke Recovery Association (SRA), Michelle Sharkey, approached me. At the time, I was at a loose end as to what to do next with my life, having almost graduated from university. I had mentioned that I would like to do for someone else what Edwina had done for me.

SRA had received a number of enquiries from younger stroke survivors about the support available for them, but found there was none catering specifically for this demographic at that time. For example, how do we cope with getting back to school/work, parental duties involving toddlers, loss of freedom and mobility, our loss of identity at the very time we are just finding one?

Michelle offered to help me if I wished to provide this support, particularly as I was a young person with the appropriate background and skills. The support group was affiliated to SRA for insurance purposes and so we could take advantage of SRA experience in setting up clubs.

Different Strokes was launched in March 2008 to help support 15–35 year old stroke survivors and has been meeting on the second Saturday of the month since. We initially met at the Royal Ryde Rehabilitation Centre, but found the environment was not satisfactory for all our members; particularly after discharge, just being in the 'hospital' setting is uncomfortable and reminiscent of times best forgotten or pushed aside.

We are such an uncommon group of stroke survivors and a geographically dispersed group. Current members come from as far east as Cremorne and as far west as Llandilo. So we went looking for a better location that was accessible, relatively central, cheap and a fun environment to meet in socially—and definitely not a hospital.

We found a little café called Lilies on the Park in Bicentennial Park Olympic Park at Homebush Bay, but inclement weather, the impossibility of hosting certain activities on uncovered tables, in a public space and the noise of other café users became issues. Following a member’s suggestion, we are now looking at using a room attached to a church hall in Haberfield. Carers, friends and interested parties are also welcome to meetings.

Members involvement with the group is on their own terms. They come and go as they are able; those that can’t make it are kept in the loop by email. All discussion follows a written agenda which I use as a memory aide. All presentations are accompanied by handouts that members can take with them as reminders. Before each meeting a reminder is sent out by email with a very brief list of the topics for discussion and after each meeting a summary of the meeting is emailed, again as a reminder and a reference.

My connections with GMCT plus the good relationships I have maintained with ex-teaching staff from university and the clinicians and allied health professionals who have treated me are a pool of people I invite to address the group about strategies to improve the lives and functionality of young stroke survivors. My public speaking engagements have also exposed me to other very useful material which I bring to the group’s attention.

**What works for us**

There are a few things I would do differently if given the chance to do it over. For example, we had the official launch before we knew if or how the group was going to be able to survive! We should have spent more time developing an official charter at the beginning, elucidating just what we were seeking to do and to achieve instead of just relying on my vision for the group.

We have learnt independence and persistence. While it is probably necessary to be affiliated to a governing agency for insurance purposes, we do not rely on it to organise or implement recruitment strategies. We use personal contacts to get our name out there and don’t expect peak bodies or organisations to just know about us. We have to tell them!

We are now working towards establishing our own website because we need to spread the news that we exist more globally and because we have found that referrals are not always being made by allied health professionals—or that some are inappropriate in terms of the age of the stroke survivor.

We also need to figure out how to deal with extending our support to people who can’t physically make our meetings, including those who have been enquiring from outside the Sydney metropolitan area. We are exploring the development of a website/facebook and are seeking funding for this through community development schemes and corporate gifts.

Even though establishing Different Strokes was not an easy task, it has been most rewarding and empowering. Bringing realisation to someone that stroke can happen to the very young; that they are not alone, that life is not over, that there is someone who can empathise and perhaps suggest strategies to make life better is what this group is about.

We support each other and together we are able to get the most from our recoveries.

Sarah Cullen won the Young Community Contribution Award of the National Disability Awards in December 2008. She also speaks at stroke management and transition care meetings and conferences and volunteers to teach English to refugees and migrants. For more information about Different Strokes, see http://www.kaleidoscope.org.au/docs/SupportGroups/Stroke.pdf
Consumers help young people make the transition

Lynne Brodie

As children with a chronic illness or disability grow up, they must leave the comfort of the paediatric health care system and enter the maze that makes up Australia’s health system. Transition programs can help them.

Adolescence can be a turbulent time for any young person. But it is even more challenging if they have the added stress of having to cope with a chronic illness or disability and find they are no longer eligible for paediatric health care. Some of the hurdles they and their family face include leaving the team who have been part of their lives for so long, finding appropriate adult services close to home, accessing multidisciplinary teams, negotiating the new service, organising equipment and dealing with changes to funding arrangements.

The Greater Metropolitan Clinical Taskforce (GMCT) Transition Care Network was formed in 2004 to improve the processes for young people with chronic health problems as they move from paediatric to adult health services. GMCT is funded by NSW Health and is unique within Australia, although other states have developed, or are in the process of developing, similar programs.

The Network includes three Transition Coordinators based at three different hospitals across NSW, John Hunter Hospital in Newcastle and the Royal Prince Alfred and Westmead Hospitals in Sydney. Each hospital is affiliated with the three tertiary children’s hospitals (John Hunter Children’s Hospital, Sydney Children’s Hospital at Randox and Children’s Hospital Westmead). The Network extends across all Area Health Services in NSW.

The Transition Coordinators can work directly with the young person and their family or liaise through an existing case manager or clinician to: help sort out any difficulties in finding or attending adult health services; provide information about adult health services; provide guidance on their attendance at clinics; make sure that they are successfully engaged in the adult service; and assist the young person to adjust to a new adult team and a new adult service.

They can also help the young person to locate a GP if they do not already have one, as studies have shown that having a regular GP improves the individual’s health, decreases hospital admissions, decreases readmission and improves mental health and coping ability.

The aim is to provide support while encouraging the young person to take on a self-management role when appropriate. For young people still at school, the coordinators can link with Department of Education’s Transition Support teachers. The coordinators focus primarily on health matters, but in reality help with other matters such as housing, school / work and relationship issues. If necessary, coordinators refer the young person to counsellors and other relevant personnel and/or specific support groups such as Diabetes Australia or Northcott Disability Services.

Current initiatives

The GMCT Transition Network is currently focused on:

- Collecting data about the number and profile of young people who are currently using paediatric services, those that are planning to move to adult services and those who have recently made the move
- Identifying gaps in transition services and collaborating with clinicians, young people and their families to determine what processes and resources are needed to bridge the gaps
- Ongoing development of a transition website
- Establishing working groups to look at specific needs of some of the larger chronic illness groups such as spina bifida, cerebral palsy, developmental disability and diabetes
- Establishing a state-wide databank to track young people as they move from child to adult services
- Providing resources for clinicians and young people such as fact sheets and checklists.

Role of consumers

GMCT is committed to involving consumers in its clinical networks. Currently, almost 30 consumers are actively involved as equal partners with doctors, nurses and allied health professionals across its clinical networks. Consumers include patients, carers, representatives of consumer health organisations and members of the community.

The Taskforce is currently looking to recruit consumers to ten of its networks.

The Transition Care Network currently has three consumers who actively contribute to its activities and several other young people are asked to provide informal advice when needed. All are confident in expressing their views and providing feedback on policies and documents. Several have spoken on their transition experience at conferences and forums and all are involved in other related consumer groups.

Three years ago the Transition Care Network held two consumer forums—one for young people and one for families; the outcomes can be viewed on the transition website (see link above) under ‘special projects’.

GMCT has found that consumers of health services bring a unique and valuable perspective, helping those working inside the health system to understand patients’ views, wants and needs. In addition, GMCT is regularly approached by intra and inter state government departments, academics, and other organisations seeking assistance and feedback from a representative group of NSW consumers; its consumers willingly contribute to external research projects and advise on consumer information materials in development.

Lynne Brodie is the Transition Care Network Manager at the Greater Metropolitan Clinical Taskforce.

Anyone interested in consumer involvement with GMCT should visit the GMCT website

The transition from childhood to adulthood can be a challenging time for anyone, and there can be added challenges when an individual is also living with diabetes. The prevalence of mental health issues amongst adolescents living with diabetes is a growing concern. The most common mental health issues are eating disorders, depression and poor management of glucose levels due to perceived stigmatisation by peers. Statistics taken from January 2009 show that the number of people living with diabetes in Australia is over 900,000; of these, just under 14,000 are under the age of 20.

Someone living with diabetes can be at greater risk of developing eating disorders for a number of reasons. For a start, they are required to monitor their diet more stringently than people without the condition, which can lead to excessive focus on diet and restrictions being placed on certain foods. Adolescents and young adult women are the groups most at risk of developing eating disorders. One of the side effects of not having enough insulin is weight loss, which is a common symptom of undiagnosed type 1 diabetes. Unfortunately there is a disturbing trend amongst adolescent women to skip insulin injections in an effort to drop weight quickly. This has serious consequences and can cause life threatening complications such as the individual falling into a coma. Eating disorders have increased risks for people living with diabetes and can result in serious short term and long term complications, including unconsciousness, loss of limbs and loss of vision. Growing numbers of adolescents with diabetes are being diagnosed with depression or anxiety disorders. The constant monitoring of blood glucose levels and diet can lead to high anxiety. It can cause feelings of frustration, fearfulness and, where complications occur, guilt for not being able to avoid them despite best attempts.

At a stage in life when individuals are most self conscious, adolescents with diabetes often feel embarrassed about telling their friends about their condition. They feel there is a stigma attached to being different from their peers. This perceived stigmatisation can mean they prefer to hide their diabetes and face the life threatening consequences rather than face embarrassment. They may avoid testing their glucose levels, or consume excessive alcohol or junk food without taking necessary precautions so that they do not feel excluded from activities with friends. Diabetes Australia is committed to turning diabetes around through awareness, prevention, detection, management and cure. It has a number of helpful resources aimed at assisting those affected by diabetes. In an effort to combat these and other issues affecting young people with diabetes, a web site has been developed to reach people under the age of 25 living with diabetes. The site provides access to chat rooms, information, resources and links to other useful sites. To access this website, go to www.myd.net.au

Diabetes Australia’s Tessie Laracy

The Family Food PATCH program improves the nutritional and physical activity knowledge, skills and practices of parents to increase the health and wellbeing of Tasmanian children. Volunteer parents and community workers are trained around the food issues and physical activity concerns of parents of both pre-school and school age children. These educators are encouraged and supported to pass on the information within their community. For example, two educators used their training to working with their school canteen manager to change the foods, reach into the community

Christine Minchin

The word ‘obesity’ is very much on the national agenda of governments and communities alike, with many ‘quick fix solutions’ advocated. However, one successful program in Tasmania goes into communities and uses peer education to promote long term changes to benefit health and well being.
Parents receive Family Food PATCH training to take back to their families and communities.

such as introducing 'Special Food days' serving chicken salads and wraps and soup days. The canteen received a grant to purchase a juicer.

Another educator was instrumental in introducing a fruit and water policy to her local school, which other schools have taken on.

After doing FF PATCH training, two educators involved in a state-wide group of grandparents who are primary carers of their grandchildren, have taken on responsibility for healthier catering for all events where this group get-together, setting a great example.

Other educators have been involved in improving what is on offer for morning teas at playgroups, influencing and becoming involved with the school canteen, increasing the consumption of vegetables and fruit in their families' diet with practical food ideas from FF PATCH and promoting water drinking.

Some have talked to parents about kids' birthday parties and fun healthy alternatives to lolly bags; for example, kids love taking home a little pot with seeds or water bottle.

**Long term community change**

Developed in 2001, the program is a joint partnership between the community sector and Tasmanian state government, including collaboration by the Tasmanian Community Nutrition Unit, Eat Well Tasmania and the Child Health Association. Playgroup Tasmania was also involved in the first five years of the program.

Peer education was proposed as a strategy that would increase community capacity and access hard to reach communities … A comprehensive needs assessment was completed and the information used to develop resources and the training manual for the program.¹

The original program dealt only with nutritional concerns of parents, but physical activities for children—and their families—were included after an evaluation in May 2006 showed a high proportion of educators wanted it. Over 200 educators have done the 25 hour course, which covers communication skills and community action as well as nutrition and physical activity information. The course was developed by community dietitians and a physiotherapist.

The educators work in the way they are most comfortable with. This can be at schools, playgroups, childcare, family day care, community groups such as neighbourhood houses, and at work. It may be one-to-one discussions, taking part in community events, working with Parents and Friends organisations to improve the school canteen or develop fruit and water policies for the school or in many other settings in the local area.

When trained as educators, parents have increased their knowledge about children’s nutrition and physical activity, developed skills in food preparation, learned to prepare healthier food and be more aware when supermarket shopping. They have changed their attitudes to nutrition and also their behaviour in such areas as limiting the time television is watched.

Many of the educators found the training gave them increased self esteem and confidence, which enabled them to take a role in making positive changes in the lives of their peers and local communities.

Many community workers who trained as educators found their confidence increased while working with programs and clients.

The FF PATCH Program was studied by the Child Health Promotion Research Centre at Edith Cowen University and considered to have great potential because of the use of parents to determine policies and content and also because of the power of other parents being influenced in a positive way though the imparting of knowledge.²

There is evidence that visiting professionals working in high needs or low socio-economic areas are frequently viewed with suspicion, while someone known and trusted by the local community is far more likely to be listened to and their advice acted upon.

**Training**

Since 2001, training has been held at 23 sites throughout Tasmania, with 13 in regional/rural and remote areas and 10 in urban areas. High needs areas have been included, and this is an on-going focus.

The FF PATCH project officer recruits volunteers, sets up new training sessions and supports the trained educators.

Interest in the course usually comes from either local parents or community workers in an area. The project officer then recruits educators after talking with key community members across the health, education, local council and community groups in the local environment. Key parent group leaders are particularly sought as they play a pivotal role in changing other parents’ attitudes and habits at a grass root level.

Training usually takes place in a venue such as neighbourhood house because a kitchen for hands-on cooking is an essential part of the program. Childcare is provided free to all participants.

On completion of the course the educators receive the training manual, a CD ROM with nutrition and physical activity information, parent handouts, useful websites, recipes, access to resources in the Child Health Association and Community Nutrition Unit libraries, newsletters and updates for trainings.
The manual includes topics such as Introducing solids, Family feud (children’s mealtime behaviour), What’s a healthy diet, Cool foods for kids, What’s in my lunch box, Mum I’m hungry (snacking) and Let’s get physical. It has lots of practical ideas, such as recipes, for the educators to use.

The training sessions are run jointly by the FFPATCH project officer, a community dietitian and a physical activity consultant. The dietitians and activity consultants provide professional support for educators wanting advice and information and also participate in update sessions organised in various state wide locations by the project officer.

The Tasmanian Nutrition Unit provides the services of three of their dietitians to support the FFPATCH program in the three regional areas of Tasmania.

**Governance**

The FFPATCH program has a steering committee made up of representatives from each partner organisation and representatives of the educators. In 2007 it was decided to review the program partnership.

The results showed a strong commitment from all the partners to the Family Food PATCH program with all partners valuing the program and its outcomes and being fully committed to the ongoing delivery of the program. The strengths of the partnership were found to be the partnership culture, commitment, ownership and management, performance management and purpose.3

As most community based organisations know all too well, the sourcing of continual ongoing funding is always a constant problem for projects as most grant funding is only available for a specific period of time. Over the last eight years, the partners have been able to source both state and commonwealth grants to run the FFPATCH program, to expand the type of training and to concentrate on the communities of high vulnerability.

This program encourages behavioural changes within communities from the knowledge base of its parents and community workers. Changes that will in the long term improve the nutritional health, knowledge and understanding of the children within that community.

Christine Minchin is the State Coordinator for the Child Health Association of Tasmania, a key partner in FFPATCH.

1 Family Food PATCH Evaluation Report 2008, Kim Jose, Alison Graham, Dorothy McCartney. p10
3 Ibid p 20

**A Growing Problem—Children with a mental illness or mental disorder**

Alexandra Rivers

As rising incidence of mental health illnesses in children and young people highlights the imperative for better information, more resources, more mental health professionals, and more research into how children should be diagnosed and treated.

While it is commonly recognised that at least one in five adult Australians will experience a mental health problem at some time in their lives, it is less well known that such problems are frequently experienced by children and adolescents.

The Child and Adolescent Component of the National Survey on Mental Health and Wellbeing recorded that 14% of Australian children and adolescents aged 4–17 experience mental health problems.1 Many of these are serious mental illnesses that interfere with the child or adolescent’s everyday life. The incidence applied across all age and gender groups, but had a higher prevalence among children in low income families, and those from step-parent, solo-parent and blended families.

Some of these illnesses, such as anxiety disorders, eating disorders, bipolar disorder and schizophrenia, can occur in adults as well as children. Others, such as behavior and development disorders, elimination disorders and learning and communication disorders, begin in childhood only and can continue into adulthood. Tic disorders usually develop in childhood. Sometimes a child may have more than one disorder.

As with adults, there are rarely physical tests to help doctors with diagnosis; mental illnesses are diagnosed based on signs, symptoms, emotions and behaviours. Diagnosis can be particularly challenging with children, since many behaviors that are seen as symptoms of mental disorders, such as shyness, anxiety, speech peculiarities, strange eating habits and outbursts of temper, can occur as a normal part of a child’s development. ‘Behaviours’ become ‘symptoms’ when they occur very often, last a long time, occur at an unusual age or cause significant disruption to the child’s and/or the family’s ability to function.

Therefore, familiarity with child development and its variability is necessary to distinguish child and adolescent mental health problems from behaviour within the accepted range of normal development. While international and Australian studies report increases in the incidence of
mental health problems in children and adolescents, it is not known whether these are ‘real’ increases caused by environmental problems, or are a result of an increasing awareness of the problems and better diagnosis, or of the increasing involvement of non-specialists in diagnosis and treatment. Mental health problems such as depression, anorexia, schizophrenia and bi-polar disorder are increasingly being diagnosed in adolescents and younger children.

However, even less progress has been made in the treatment of children with mental disorders than for adults with mental health problems. Which treatments and dosages work best for which conditions in which children are still being investigated. Even the application of the adult diagnoses to children is questioned. For now, many of the treatment options used with children are the same as those for adults. These include many medications (anti-psychotics, anti-depressants, stimulants, and anti-anxiety and mood stabilizing drugs), psychological therapies (behavioural interventions, cognitive behaviour therapies, family or group therapies) and also art, or play therapies, and therapeutic parenting.

There is concern about the use of psychotropic medications with children, as there has been little research on the impact of these medications with children despite the known metabolic differences between children and adults. These medications have known behavioural, physical and neurological side-effects, as well as stigma effects. The long term impact of their use with growing children is little researched. Guidelines recommend that the diagnostic categories and relevant medications be used with children from six years only, and then only after all non-medical interventions have been exhausted. However, the number of children being treated with stimulants, anti-psychotics, antidepressants and other psychiatric drugs is rising, despite the limited research and lack of comprehensive clinical practice guidelines.

There is concern that psychotropic medications seem often to be prescribed as a first option. Their use with preschool-age children is of particular concern. Overseas data and anecdotal reports in Australia indicate that preschool children are receiving such medications, often in combination, despite the ethical and legal implications of the lack of research and clinical guidelines for their prescription.

Because childhood diagnoses must be considered in the context of an individual child’s development, and there are no objective diagnostic indicators, it is recommended that only specialist practitioners experienced with diagnosis in children prescribe such medications, and if possible, a second opinion is sought.

Mental health disorders usually require ongoing treatment. Best practice mental health treatment advocates community based early intervention, with the child and their family having ready access to professional help, though hospital-based or residential treatments may sometimes be required. Additionally, caregivers experience significant emotional distress and life disruption having and caring for a child with a serious mental illness, so interventions are complicated by parental grief reactions which also require support.

Child and adolescent mental health is the Cinderella of our health system, with rural and remote areas and indigenous communities particularly bearing the brunt of the shortage.

The dearth of child psychiatrists, child psychologists and mental health workers to support caregivers, is a significant problem for the Australian health system. The lack of specialist mental health practitioners and of specialist hospital or residential facilities in both the public and private health systems prohibits appropriate diagnosis, treatment, and educational and other supports for many children and their families. This increases their burden of illness, the burden of their care—and their burden of stigma.

We need research into the use of psychotropic medications with children and adolescents, updated clinical practice guidelines and many more child psychiatrists and child psychologists. It is also urgent that general practitioners, who are increasingly responsible for community mental health care, are made more aware of the issues relating to mental illnesses and disorders in children and adolescents, the guidelines for their diagnosis and treatment, and the treatment options, and assisted to develop the skills to recognise and treat, or refer, mental health problems in this vulnerable population. It is also urgent that such education be available for parents and caregivers so that they can be more informed in the health choices they make for their children.

2 Ozgul, S., Parental Grief and Serious Mental Illness, (Draft Report) School of Psychology The Australian National University, Canberra, 2003.
ADHD medicine—Making the choice

Janet Hutchison

There is much confusion and controversy around the use of ADHD medicines. However, for people with ADHD, medicines make a huge difference to their lives. Different medicines have different advantages.

So, you’ve made an appointment for your son or daughter’s ADHD assessment and now you’re wondering about medication. Or maybe you’re a young adult with the same questions. Are they safe? Will they dampen creativity? What evidence is there? This article is a brief summary of the main ADHD medicines. For more detailed information, ask a paediatrician or psychiatrist.

The first study of children with what we call ADHD was published by physician George Still in 1902. He thought they had a neurologically based, ‘serious defect of moral control’. Since 1936 stimulant medications have proved an effective and safe treatment for ADHD in all ages. Ritalin (methylphenidate) has been used for treatment of ADHD symptoms in children since 1961.

Medications work best as part of an individually tailored package that may include counseling, psychological and educational interventions. Any one diagnosed with ADHD should ask for the evidence supporting these interventions before committing to them. In some circumstances, medication may be enough.

Medication is a tool that consumers can choose to help them achieve their goals. If it’s not helping, then don’t take it. However, it may be worthwhile to discuss this with the doctor in case changing the dose or changing to another medication may help.

Which medicine?

Methylphenidate (Attenta, Concerta, Ritalin, Ritalin LA) comes in short acting and long acting formulations. Attenta is the generic version. One dose lasts between two and four hours. Occasionally, Attenta may work where Ritalin doesn’t. Ritalin LA delivers an immediate dose and a delayed release dose. Concerta slowly releases methylphenidate for up to 12 hours. It has a tapering off effect as it wears off that can be beneficial.

Long acting medicines have two principal benefits. Firstly, privacy is protected because children and young people don’t have to take medications at school, work or in other public places. Secondly, there are fewer problems with missed or delayed doses. While others worry that stimulants are addictive, the reality for most people with ADHD is frequently forgetting to take it.

ADHD often impacts negatively on social interactions; that is, individuals with ADHD may impulsively say things they regret, or inappropriately express anger or other emotions, or deliver an unappreciated monologue or simply not respond as they would like to what others are expressing. While the medicine’s working, they can stop worrying about this kind of thing. But it can be unpleasant when they realise the meds have worn off only after they’ve said something they really regret. When their meds wear off, children are more likely to reward other’s provocation by reacting without thinking first, making them vulnerable to ongoing bullying.

Short acting preparations are sometimes preferred by those who wish to use them just for homework, paperwork or tidying their room but prefer to be off it at other times, say while playing sport. Consumers may be able to get a prescription for both short acting and long acting meds so they have a choice on a particular day.

Dexamphetamine is equivalent to short acting Ritalin but lasts from three to five hours. A long acting version can be obtained from a compounding pharmacy in your state or territory. Atoxomexetine (Strattera) is a non-stimulant recently introduced for treatment of ADHD. It inhibits reuptake of norepinephrine. It may cause loss of appetite, sedation or sleepiness or flu like symptoms. It has slightly different effects than stimulants and may be better for some individuals.

Benefits

Up to 90% of people with ADHD benefit from one or other stimulant medication. If one doesn’t work then the other might. Both have similar benefits; for example, they ‘calm’ hyperactive behaviours, make it much easier to stick with and complete the task in hand, make reading easier and more enjoyable, and improve social interaction.

Side effects

Alarmist media reports overstate side effects. Side effects are mostly minor such as reduced appetite. If they are troublesome the medication should be stopped and the prescribing doctor contacted. The side effects will probably disappear once the dose has worn off. There is no way of predicting which side effects (if any) will affect a particular individual.

It’s important not to give up quickly but explore different options to find what works best for the individual.

Reports of sudden cardiac death are exaggerated. However, children with known heart problems or a family history of cardiac problems should be evaluated carefully by their paediatrician or a heart specialist.

Very high doses can cause thought disorders and other reactions. These are rare at the low doses prescribed for ADHD (prevalence estimated at less than 1%) and last only until the dose wears off.

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As for creativity, most people on stimulants report that these medications allow them to harness their creativity effectively. Some children or young people report feeling flat in social situations. The individual or parent can weigh up the pros and cons of taking medications when this happens. Compromises such as taking short acting meds for homework can work.

Prescribing

Authorities are required for prescriptions for stimulant medications. Each state or territory has its own scheme. Unfortunately, prescriptions can only be filled in the state or territory they were obtained from.

A serious concern for those over 18, and many older teens already taking Concerta or Strattera, is that they are not available on the PBS from 19 years of age onwards. Young people who are studying or starting work usually can’t afford to pay $100-150 per prescription; most parents can’t either. ADHD is mostly a lifelong condition so this situation is totally unacceptable.

Final Note

If there’s a media scare about stimulant medications, people using ADHD medicines can always ring up their doctor or local ADHD support group. These scares are usually beatups, but they may not be. Local support groups should be able to give more information. They may have copies of related materials such as peer reviewed journal articles not available free online.

Local ADHD support groups are interested in what works, rather than promoting a particular remedy. We keep in touch, so people interested in ADHD can access 20 years of combined experience and knowledge wherever they live.

Janet Hutchison is the Vice President of the Canberra and Queanbeyan ADD Support Group. She has no commercial interest in any ADHD remedy.

There are ADHD support groups around Australia. For more information, email addact@shout.org.au or visit www.addact.org.au.

1 References for most of this information is Russell A Barkley, Taking Charge of ADHD: The Complete Authoritative Guide for Parents. See also the Draft Australian ADHD Guidelines and the Supporting Literature Review and Additude Magazine. at http://www.additudemag.com/adhd/article/5253.html

Young, homeless people respond to co-ordinated care

By Penny Gibson

Young, homeless and at-risk young people have complex health needs that can only be properly addressed when their social needs also are met. Adelaide’s Streetlink has an integrated model of care that meets those needs—and sets an example for other primary health care services.

The Streetlink Youth Health Service of Adelaide offers its young clients an integrated health care service that recognises that physical health needs cannot be separated from social and mental health needs.

The service adopts a social rather than purely physical view of health, with the clients’ social context playing a large part in the way the service operates. Clients are 12 to 25 years old and their children.

Most are from disadvantaged backgrounds, marginalised, homeless or living in care, refugees or homeless shelters, or are at risk of doing so. Some have grown up in the city and others have moved from the country. Many have complex needs, including drug, alcohol and/or mental health issues.

Because they often have many interacting problems, Streetlink looks beyond physical health and provides many other supports that are linked. It is a drop-in service (except the GP) with a doctor, two nurses, two community workers, six alcohol and other drug counsellors (including one for co-morbidity, two drug and alcohol counsellors and two family counsellors) and two living skills counsellors. Because of a growing need, there are plans to explore options regarding mental health services.

The service, which is operated by the Uniting Care Church, aims to provide the support each young person needs to be able to move into the mainstream community.

Take, for example, a young homeless mother with mental health issues. While dealing with the medical and mental health issues, Streetlink helps her find accommodation and then goes with her to the new community and helps her access Centrelink, find a GP and local community services. At the same time, a living skills officer provides outreach skills such as cooking, cleaning and banking.

Support from the different elements of the service is ongoing depending on the complexity of each client’s need and their ability to cope.

Streetlink was established in 1986 in response to the growing numbers of youth using the UnitingCare Wesley Adelaide facilities. It originally provided an alternative youth focussed drop-in service. Following the Burdekin Inquiry into homeless youth in 1989, it received funding to provide health services for young, marginalised people. The success of the Streetlink model of care has secured it funding from the federal and South Australian governments.

There is no shortage of clients. The homeless community is fairly small and word spreads quickly. The staff are
often seen during their outreach work at the homeless shelters and other places where their clients tend to congregate. Other community and government services refer people to Streetlink.

Many clients are actively ill and have a high level of need when they first come in. In addition to the normal adolescent developmental issues, they have the chronic problems associated with transient living, such as alcohol and other drugs issues, mental health issues, infections and wounds.

People who live rough and don’t have stable accommodation usually have inadequate nutrition and related poor health. They often have mental health issues that go back many years; because these have never been dealt with, there has been no early intervention. These mental health issues are often complicated by alcohol and other drugs and homelessness.

**Meeting on their terms**

The service is successful because it deals with young people on their own terms and across their different needs. Streetlink recognises that life does not move as easily for its clients as it does for others; as a result, their needs and behaviour often don’t fit within mainstream service expectations and tolerance levels.

Streetlink has developed strategies to support these clients. For example, when they miss appointments because there is so much else going on in their life, Streetlink texts them to reschedule and then to remind them about appointments and follow-up. Some clients are seen outside the centre for their—or others’—safety.

Clients have often had negative experiences with the mainstream health system, leaving them feeling intimidated and powerless. So when they need to go to a hospital or specialist, or move into a new community, the service tries to refer them to services that understand their needs and are welcoming. Often an outreach worker or nurse will go with them. They often find that they must act as an advocacy service for their clients, either as individuals or as a group.

Another factor in the service’s success is its accessibility. It is centrally located, the layout is very youth oriented and the staff dress casually. Staff are non-judgmental and recruited, trained and supported to deal with clients on their own terms.

Clients can come back as often as they need—until they reach 25. Some may come several times a month, and then not for a while as things go better for them. The service has strategies to help clients they feel are becoming too dependent on it.

Communication is a crucial element of service delivery. Because of the importance of spending time with the clients, interacting and building rapport with them, the service has a 30 minute minimum appointment time with counselling sessions usually lasting at least an hour.

‘We recognise they are the expert on their life and work from there,’ the services GP Natasha Kuller said.

‘We provide them with information and talk through the options with them about what they want. The care is based on where they are at, at that time. For example, they may recognise they have a drug dependency, but may opt for harm minimisation rather than full-scale rehabilitation.

‘It’s also very important for us to be honest with them. They are very streetwise and see through any rubbish. We tell them our limitations. Most importantly, we respect them and we gain their respect, to which they respond.’

Streetlink has an ongoing quest for funding, but the fact the funding has been forthcoming to allow the service to grow is an acknowledgement of the need for it.

With primary health care on the national radar, the service expects to keep building. The big need now is in mental health and Streetlink is looking for ways to meet that need.

*This article is based on an interview by CHF Communications Advisor, Penny Gibson, with the Team Manager of Streetlink Youth Health Service, Sam Laubusch, and its GP, Natasha Kuller. Streetlink provides services to homeless and at risk young people across metropolitan Adelaide through its city office or in an outreach capacity.*

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**Caring for young carers**

*Natalie Tolley and Annemarie Ashton*

Young carers need to juggle their caring responsibilities with their need for education, friends and a social life. Research in the Australian Capital Territory shows that caring can be affecting their life, but that supports are available.

When does caring about someone in your family become caring for them? This question applies to a hidden generation of ‘Young Carers’ who have an essential role in our society—and yet go largely unnoticed.

Young carers are children and young people under the age of 25 who provide care for a family member with a disability, illness, mental illness or an alcohol or other drug problem. They may be the only person providing care, or they may contribute to providing care alongside other family members—or for those family members.

Care can include domestic assistance (such as cooking, shopping, laundry and housework), personal care for the care-recipient (including bathing, helping with mobility, and toileting) or nursing care (such as administering medication). They often provide significant levels of emotional support. They may take on the care of younger siblings, from getting them to school to making dinner and getting them to bed.

The Survey of Disability, Ageing and Carers indicated there were 170,600 young carers aged under 18 and 380,000 young carers aged under 26 providing care to family members in Australia in 2003.
Health, education and relationships

ACT research indicates that the young carer role can be stressful and may have significant impact on health and wellbeing. Some young carers are time poor and the demands of caring can lead to a lack of sleep. In fact, 50% of respondents participating in the study reported experiencing significant fatigue due to their caring role.

However, this is not a universal experience, as others reported a positive impact on their health, making them feel stronger and more active because they were so busy.

The research found many young carers experience high levels of anxiety caused by worrying about their caring role and about the health of their family member. Some also express concern at the possibility of inheriting a family member’s illness or condition.

Education is of great concern to many young carers. Young people accessing programs through Carers ACT often disclose they may be late to school, must leave in the middle of the day to make sure their parent has their lunch, or may miss school altogether because they are needed at home.

They can also be distracted at school because they are worried about the care recipient’s health or because they are tired. Young carers falling behind in academic achievement experience more stress. Carers ACT is concerned they may choose to leave school because care demands make it too difficult for them to stay connected to the education system. In 2006, the Institute of Child Protection reported that only 4% of young carers aged 15-25 were studying, compared with 23% of the broader population.

Being a young carer can also lead to social isolation. While some have good connections with their peers, others find that they do not have time for social interaction. Losing contact with friends and peers can contribute to stress. Family relationships can also be affected. While some families find that they have closer family relationships due to the caring situation, others find the stress strains relationships.

Support for young carers

Health, education and social impacts can all be reduced when young carers are provided with supports that are suitable for their age and meet individual needs. Carers ACT provides various supports to help people provide care.

The Young Carers Program offers case coordination, access to flexible and appropriate respite options and support groups. Case coordination is particularly important as young carers can find the maze of services difficult to navigate. Having a trustworthy and friendly person, who is able to do the leg work for them, can be a great help. Case coordination gives young carers more time, as they have so many other roles and duties to juggle.

Carers ACT receives funding from the Australian Government to support young carers at risk of not completing their secondary education through a range of flexible respite options. Appropriate respite support gives them a greater chance of staying connected at school and reduces some of the load of their caring role. Respite is tailored to meet the individual needs of the young Carer and their family. While some might access tutoring to help them catch up with their school work, others get help with domestic support such as meal preparation during exam time. Young carers can also access support to help look after the care recipient while they are at school.

Contact with fellow young carers is often helpful as they can gain support and knowledge from peers who empathise with the demands of a caring role. Carers ACT currently runs two support groups. The 7-10 year old support group started from a Seasons for Growth program, an age-appropriate short course about the changes that occur when someone starts providing care. The group offers a gentle introduction to care support in a friendly and fun environment. Participants can meet other young carers and have some respite from their caring role. The 12-15 year old girls group was established in 2008 and meets monthly to look at self-care skills, share knowledge and network with other young carers.

Despite the availability of good supports, there are still areas of unmet need. Carers ACT is currently looking at ways to improve knowledge of young carers aged 18-25, to provide appropriate support services and help them to transition into adult carer support services if required. More needs to be known, as anecdotal data from Young Carer services around Australia indicates that many 18-25 year olds may be caring for a partner or a child rather than a parent or sibling. Some may have taken on the sole role of caring for a sibling. Additionally, these young people may also be transitioning from the education system into the workforce, or from secondary school into tertiary education.

Consider the following example based on de-identified case data:

Beth, 18, cares for her father who has terminal cancer. She recently finished year 12 and hoped to attend University, but she has to work to support her father. She thinks that trying to juggle study, work and caring for her father would be too difficult. Her boyfriend, while trying to be supportive, doesn’t really understand why Beth stays home to look after her father and cannot go out as often as they used to. Beth really needs to talk to someone who understands what she is dealing with. She also needs information on services to help her care for her father as his illness progresses.

Natalie Tolley is the Young Carers Coordinator and Annemarie Ashton is the Policy Advisor at Carers ACT. Carers ACT Young Carer program is supported by the Australian Government through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and by the sponsorships of GE Shaw & Associates and Ernst & Young.

2 Moore, T. (2005) Reading between the lines: Listening to children and young people about their experiences of young caring in the ACT. Canberra: Youth Coalition of the ACT.
Think pregnancy—think immunisation

Hailey Shaw

Whooping cough? We got rid of that decades ago...didn’t we? So why is Australia currently seeing a resurgence in whooping cough that is killing some babies and leaving others very, very sick?

We all think about immunisation for our children, but we need to also think about how to keep adults immunised so they can protect the children they come in contact with.

Anyone living or working in close contact with babies and children need to keep up their immunisation, including parents, grandparents, childcare workers, maternity nurses and other health staff.

Immunisation for mothers and women planning pregnancy should be routinely considered. Taking vitamins, stopping smoking and reducing alcohol and caffeine intake are well known health benefits. Pregnant women or women planning pregnancy are also encouraged to be up to date with Pap smears, eat a balanced diet and have routine screening tests to check immunity to rubella (German measles) and hepatitis B.

However, is screening for vaccine preventable diseases enough or should we look further? In particular, we need to revisit whooping cough.

Whooping cough (aka Pertussis) is a highly contagious infection that is easily transmitted through airborne particles or direct contact with respiratory secretions such as spit. It is a serious and potentially fatal disease with 18 deaths in Australia between 1993 and 2005; 16 of those fatalities were in babies less than 1 year old.1

The National Notifiable Diseases Surveillance System reported 14,468 cases across the nation in 2008 (more than double 2007) and 4,432 for just the first two months of 2009.2 In September 2008, NSW Health put out an alert following almost 3,000 cases that year - double the number for the same period in 2007.

Children are immunised against whooping cough at ages 2, 4 and 6 months and 4 years. Following increasing numbers of adolescents being affected in the community, a booster dose of this vaccine was additionally introduced as part of the National Immunisation Program in January 2004 for 15-17 year olds.3

Outbreaks occur approximately every three to four years and in Australia many of these cases occur in adults and adolescents who have waning immunity even if they were fully immunised as children. In 2004-2005 more than 70% of pertussis notifications were in those 15 years or older.4

Adolescents and older people are unlikely to suffer the serious complications that infants do. They may not realise they have the infection because they often do not have the characteristic cough with its whoop when a breath is taken. The great danger is that they can infect very young, not fully immunised babies.

Who should be immunised?

A national survey of babies hospitalised with pertussis in 2001 found that parents were the source of infection in 54% of cases and other family members, such as grandparents and childcare workers, were presumed to be the source of infection for others.

Should we further the current routine screens for women who are planning a pregnancy to include receipt of a booster dose of pertussis vaccine?

By ensuring immunity of people in close contact with babies, it is expected the babies will be protected. The National Health and Medical Research Council now recommend this occur. Indeed, the Northern Territory Department of Health and Community Services has taken this recommendation a step further and, since late 2008, funds a booster dose of vaccine for every new mother in hospital maternity units.

It can be hoped that any positive impact from this campaign will provide momentum for similar changes to the National Immunisation Program Schedule.

The lack of visibility of many once common infectious diseases in the community such as polio, diphtheria and influenza B disease have allowed us to temporarily forget the very serious outcomes of such illnesses.

Australia’s high childhood immunisation rates cannot be relied upon to provide lifelong protection or to protect all, especially those who are either too young or too old to be fully protected.

Immunisation must be considered across the whole of life, particularly by pregnant women who wish to give their children the best possible protection.

Hailey Shaw is the Immunisation Program Officer at the ACT Division of General Practice.

Consumers as providers—donations that save children’s lives

Russell McGowan

With many more children needing transplants than there are donors, we need to increase the number of people willing to be donors and be more efficient in our collection and use of donated blood, tissue and organs.

There’s nothing a newspaper or tabloid TV station loves more than to tug at our heartstrings with the story of a young child whose life is at risk because of a faulty blood supply or organ failure. Through circumstances entirely beyond their control, helpless infants and their anxious parents suffer horrendous reductions in their quality of life as life threatening conditions worsen pending availability of human organs or matching tissue that will turn their lives around.

But while we sit and watch such stories with horror, there is much we could do to improve the availability of organs and blood and thus give many children—and adults—a new life.

The Australian Red Cross Blood Service, which is entrusted by governments to collect blood from donors in Australia, has declared this 80th year of their work ‘The Year of the Blood Donor’. To motivate people to think about donating blood, Red Cross has published some inspiring stories like this one on its website:

Born at just 27 weeks and 950g, Courtney from Adelaide spent seven weeks in intensive care and needed three blood transfusions to give her the best chance at survival. She is now a gorgeous toddler and her parents believe that Courtney may not have pulled through if it wasn’t for blood donors.

Transplantation of human organs and tissue can similarly transform the lives of individuals and the families who care for them.

The government and a range of community organisations encourage all Australians to register their consent for organ donation on the Australian Organ Donor Register, which is administered by Medicare Australia. They also ask people who are considering registering as donors to discuss their decision with their family so the family knows their wishes.

How it works

When a patient passes away in a way that makes them suitable to donate organs or tissue, the Australian Organ Donor Register is checked. If there is no written or verbal objection to donation or the person is not registered, the family is given information about the donation process and asked whether they consent. Donation does not go ahead without the family’s agreement.

Lungs, heart, liver, pancreas and kidneys may all be considered for organ donation. Tissue which can be transplanted includes corneal grafts to restore failing eyesight; skin to treat serious burns; bone, when bone grafting is necessary; bone marrow to restore the marrow of people battling leukaemia and other cancers; heart valves for use in heart surgery. Some of these can be ‘harvested’ from both living and dead donors. I was fortunate enough to have a live sister to donate bone marrow for me some years ago.

The most common transplants for children are kidneys and bone marrow, but it is not unusual for livers, hearts and lungs to be transplanted into children as well. These are more problematic as size is important and organs from adult donors are, therefore, often unsuitable.

However, too few Australians have actually committed themselves to signing on to the donation register. Too few willing donors have actually prepared their families and loved ones to make a timely decision; this needs families to discuss uncomfortable issues such as death and dying.

While no-one would bemoan the reduced number of child donors because we have reduced road trauma and other accidental deaths of children and young people, this means the pool of potential child donors is smaller.

Furthermore, the co-ordination of donations once a death occurs is very complex.

Australian organ donation rates lag behind many other nations, despite high levels of community support. Some sobering statistics include:

• Australia is currently ranked only 17th in the world in relation to organ donations
• In 2007, 198 people became organ donors and approximately 668 people received transplants
• As of January 2008 there were 1757 people in Australia on waiting lists for a transplant
• In 2006, the average waiting time was 205 days for a liver transplant, 145 days for a heart transplant and 187 days for a lung transplant.

Hope in new authority

Late last year, the Rudd Government announced a new co-ordinating authority, the Australian Organ and Tissue Donation and Transplantation Authority. While the number of centres where transplants of organs or tissue can be transplanted will remain limited, there will be more capacity to collect organs.

Support will include dedicated organ donation specialist doctors and other staff in public and private hospitals and new funding for hospitals to meet additional staffing, bed and infrastructure costs associated with organ donation. There will be enhanced professional education programs, consistent clinical protocols, ‘clinical trigger’ checklists and data collection for organ transplants in hospitals.

As importantly, there will be national public awareness and education campaigns and counselling for potential donor families.
Improving the system

We need a transparent system which ensures that donation and transplantation processes minimise wastage of donated organs and tissue, and maximise opportunities for life saving transplants.

Processes must not be as laissez faire as they are in the blood sector, where too much of the collected blood is wasted by those delivering services to those needing blood and blood products.

While one in three Australians will need blood at some stage during their lifetime, only one in 30 give it, even though giving blood is quick, free and painless. The Red Cross is always looking for more donors. In fact, it says Australia needs around 21,000 donations every week—that’s 3000 every day—to ensure there is enough blood for the people who need it.

Much of this goes to fractionation, or preparation of blood products to meet demands of people with haemophilia or immune system disorders who require products like clotting factors VIII or IX, or intravenous immunoglobulin.

However, a seminar conducted by the National Blood Authority last year made it clear that much of the blood collected for fresh blood transfusions is wasted through storage and distribution problems, or used unnecessarily in surgery or in transfusions in circumstances where alternative therapies would possibly give better outcomes for consumers. The same may be true for some of the much more expensive fractionated products.

One of the reasons postulated for this is that there is currently no cost associated with the use of blood or blood products, although there are considerable costs involved in making the resources available (perhaps as much as $100 per unit of fresh blood transfused).

So, in supporting the introduction of this new donation authority and encouraging people everywhere to sign on to the national organ and tissue donation register, Australians need to be assured there will be robust processes surrounding the organs and tissue that we donate to change the lives of our fellow Australians who are currently awaiting transplantation.

I wish the authority well in its inaugural year.

Russell McGowan is a CHF Governing Committee member, the immediate past-president of Health Care Consumers’ Association of the ACT and a consumer representative on several committees.

Palliative care for children

Jenny Hynson

Access to palliative care for children is hampered by its association with death, but the move to include it, where relevant, as a component of treatment that helps children and their families ‘hope for the best, but prepare for the worst’.

Palliative care is specialist care provided for all people living with, and dying from, an eventually fatal condition and whose primary goal is optimising quality of life. Although we are increasingly familiar and comfortable with the term palliative care, we most often associate it with the care of elderly patients and those with cancer.¹

The reality is, however, that around 2,650 children across Australia could benefit from palliative care at any one time.

Many families worry that accepting palliative care means ‘giving up’. In fact, palliative care can be provided along with ongoing efforts to treat underlying disease.

All too often the referral to palliative care services is perceived as the time when hope is abandoned.

Understandably, this perception is a barrier to accessing care. Research in the area of paediatric palliative care has shown the majority of parents do not abandon hope that their child might survive until very late in the child’s illness. These parents would not consider that their child has a ‘terminal’ or ‘eventually fatal illness’ and may reject services that use such a description.

Furthermore, many childhood conditions are associated with very uncertain prognoses. Delaying the provision of palliative care until there is absolute certainty about the outcome means key supports will be provided too late or not at all for many children.

For these reasons, providers of paediatric palliative care advocate an integrated approach in which elements of palliative care are provided alongside ongoing efforts to modify or even cure the underlying disease. This allows families to ‘hope for the best but prepare for the worst’ and enables a redefining of hope to ‘hope for the best quality of life possible’.

The World Health Organisation has recognised that paediatric palliative care is different and has articulated a definition that recognises and embraces the compatibilities of curative and palliative approaches.²

The incorporation of palliative care into the ‘whole of health’ agenda is also the direction in which Palliative Care Australia is influencing change in the health sector.

What is palliative care?

There are many misconceptions around the term ‘palliative care’, including that it is limited to the end of life, only for elderly people or those with cancer, is passive and little more than ‘hand-holding’ and involves the use of medications that shorten the patient’s life.

In fact, palliative care has much to offer. The focus is very much on improving the child’s quality of life; on making the best of the situation they are faced with.

Palliative care involves the active use of state-of-the-art medications and techniques to treat pain and any other symptoms that prevent the child’s enjoyment of life. It provides social,
emotional, cultural and spiritual support to the sick child, their parents and siblings. Although it does include providing care at the end-of-life, it is not limited to this and many children receive palliative care for long periods of time.

**Children’s different needs**

In developed countries like Australia, the average person rarely encounters childhood death and may be ill-prepared to support a family whose child has been diagnosed with an ‘eventually fatal’ illness. People often feel uncomfortable and awkward and may even avoid contact for fear of saying or doing the wrong thing. This can lead to families feeling isolated at a time they most need support.

Children’s palliative care needs are great. Children tend to suffer from a diverse range of ‘eventually fatal’ illnesses, many of which are rare. Fewer than half have cancer. Many have disorders affecting the nervous system which slowly progress over years causing disability, sleeping and feeding difficulties, and seizures. Some of these conditions are inherited and more than one child in the family may be affected.

Parents are very involved as direct caregivers and decision-makers for their child, making difficult decisions regarding what treatments should and should not be provided. Care is often required around the clock over many years and many parents need to become familiar with complex equipment in order to keep their child at home.

Childhood is a period of rapid physiological, emotional and psychological development spanning the newborn period through to adolescence. Just as illness affects development, developmental issues influence how a child experiences illness.

How children understand illness, how they communicate their fears and hopes, and how involved they are in decision-making are all affected by their developmental level. Play is extremely important as it is the child’s way of working through the issues confronting them. Similarly, kindergarten and school have a central role in a child’s life, providing the reassurance of a daily routine and important opportunities for mastery, distraction and social interaction.

**What palliative care offers**

The provision of palliative care is not limited to the sick child. Parents require emotional, practical and spiritual support during the child’s illness and into bereavement. Young siblings also have their own fears and needs. Grandparents suffer the grief of losing a grandchild but also the pain of watching their own child go through such an experience.

Palliative care is generally provided by a team of specialist doctors, nurses, social workers and other health professionals. Services specifically designed for children are based at most of the major children’s hospitals. Support is often provided in both the hospital and community setting, involving a range of primary care practitioners. In addition, some states have special hospices available for children that can provide respite and end-of-life care and support for the child and family.

These interdisciplinary teams are responsible for providing:
- management of physical symptoms such as pain
- advice and assistance in making important decisions regarding the child’s care
- care in the home environment if that is what is desired by the family
- emotional, psychological and spiritual support for the child, parents and siblings
- assistance in accessing respite care and with care planning and coordination
- advice on how to talk to children about illness and death and bereavement support, and
- support for the child to go to school or access music or art therapy if that is what they would like.

There are many resources and books for parents and children in this situation. Journeys: palliative care for children and teenagers seeks to take parents through the journey from diagnosis to bereavement and beyond. It was written in consultation with paediatric palliative care specialists and parents and is intended to provide support during this time.

**Gaps in service provision**

A key challenge for providers of palliative care is that referrals are often received late or not at all. Many health providers and families believe palliative care is only for those who are in the end stage of their illness. Compounding this are difficulties in predicting the course of illness and a desire to ensure no stone has been left unturned in efforts to cure the child.

A lack of understanding of what can be offered results in many children who might benefit from palliative care being unable to access this important resource; for example, pain management. There is considerable evidence to show that even in the most progressive health care settings, pain and other symptoms continue to be inadequately recognised and treated.

Another important consideration is the nature of the underlying illness. Many children suffer from conditions that...
Stillbirth: Striving to explain the unexplained

David Ellwood and Vicki Flenady

A stillborn baby is the tragic outcome of what we all expect and hope to be a very joyous and happy occasion—the birth of a new life to love and watch grow. Every year approximately 2100 pregnancies in Australia result in a stillbirth - the equivalent to six babies a day, or six Boeing 747s with 350 passengers each. While discussion surrounding this global health problem remains overlooked in the Australian public sphere, stillbirth rates are not declining—and have not for 20 years. In one third of stillbirths, the cause of death is unknown, occurring unexpectedly in an apparently healthy mother and baby. It’s important to investigate the causes—for parents, clinicians and researchers—and explain them to current and future parents.

In Australia stillbirth is defined as a fetal death that occurs at or after 20 weeks gestation or 400 grams and over. The major causes are birth defects (genetic or chromosomal abnormalities), maternal conditions, spontaneous preterm labour and placental abruption. Fetal growth restriction (FGR) is a common finding at the time of stillbirth.

FGR is associated with certain genetic defects, fetal infections, maternal smoking, hypertension, obesity and diabetes. Better methods for detecting FGR during pregnancy may hold hope for further reductions in these deaths. Perhaps the most crucial area for researchers is the deaths that remain unexplained.

Exploring unexplained stillbirth

A lack of quality information and a shortage in funding are the two key constraints to unlocking the unknown causes of stillbirth in Australia—and world wide.

The Australian and New Zealand Stillbirth Alliance (ANZSA), a regional office of the International Stillbirth Alliance (ISA) which unites researchers, health care professionals, parents and bereavement specialists, is attempting to change this.

The quality of information available on the causes of stillbirth is a major barrier to further reducing the numbers of unexplained stillbirths. This is largely due to the fact that the majority of stillbirths are inadequately investigated and therefore important information may often be missed.

Investigating unexplained stillbirth has its problems. It requires information to be organised by comprehensive national data collection and classification processes, but a nation wide data repository is expensive to establish and maintain. It is also expensive to conduct high quality autopsies. In addition, autopsy rates are very low (30% in Australia).
Educating clinicians on how to communicate to grieving parents about autopsy requires time and resources which are lacking in maternity care settings in general.

If researchers can solve these problems they will have a better understanding of the unexplained, potentially saving two babies a day in Australia.

**Potentially modifiable risk factors**

Although a large portion of stillbirths remain unexplained, there are many factors which have been identified as increasing the risk of stillbirth. Many of these risk factors can potentially be avoided or modified.

ANZSA, with support from the Stillbirth Foundation Australia and the Department of Health and Ageing, has recently conducted research into identifying potentially modifiable risk factors for stillbirth in Australia and New Zealand.

Their most recent study found that maternal overweight (BMI of 25-29.9) and obesity (BMI over 30), smoking, and women aged 35 or older were the most important modifiable risk factors for stillbirth in Australia and New Zealand; 12.5% of stillbirths are attributed to overweight mothers, 13.5% to mothers who are obese and 8.5% to mothers who smoke during their pregnancy.

Emphasis needs to be placed on communicating these modifiable risk factors to potential parents in national public awareness campaigns.

**The importance of investigation**

Investigations into stillbirth are crucial as they may provide an explanation for the death to the parents and families who need to know what went wrong. This relieves suffering, enables better counselling about recurrence risk and gives hospital management an insight into better practice for future pregnancies, even when an autopsy does not provide a reason.

The Perinatal Society of Australia and New Zealand (PSANZ) Guidelines offer a national approach to investigation (as well as many other aspects), allowing for more comprehensive information for researchers. But while good quality clinical guidelines and their tools exist, it takes more than just making them available to make a difference in maternity care.

As important, there is no Australia wide unit record data available that incorporates the PSANZ classification. A national perinatal mortality audit data collection meeting was held in December 2008 to reach national consensus on the PSANZ perinatal audit form for use in clinical review; this provides a unique opportunity to strengthen jurisdictional and national data on perinatal mortality in the future. Ultimately, this will better equip researchers to conduct research into unexplained stillbirth.

**The importance of stillbirth autopsy**

Collecting the evidence, understanding the causes, and implementing preventative measures are at the forefront of the efforts towards prevention.

Autopsy is widely acknowledged as the gold standard to investigation; however, declining autopsy rates are restricting researchers from gaining evidence into potential causes. Australia’s current national autopsy rate is 45% below the Royal College of Pathologists recommended rate of 75%, so it is no wonder one third of stillbirths are unexplained and we know so little.

A key factor for low autopsy rates is the lack of parental consent through poor communication and consenting procedures. Parents face an intrusive process that requires an understanding of detailed consent procedures in a state of grief, making clinicians reluctant to place further burden on the parents.

We need to train clinicians how to communicate sensitively with parents about all aspects of autopsy so they can make the right decision for them.

Stillbirth autopsies, placental examination and clinical examination methods provide the evidence we need, giving an insight into potential causes and allowing for the implementation of protocols to improve practice.

**Training clinicians**

The PSANZ Guidelines provide guidance for clinicians in areas of investigation, including autopsy, classification, placental and clinical examination, and communication with parents. A telephone survey of senior midwives and doctors in birth suites across Australia and New Zealand in 2007 found low awareness of the guidelines and less than optimal uptake of the recommendations into practice.

An educational program has since been developed by ANZSA and the PSANZ Perinatal Mortality Group on the assumption that when clinicians are informed and compliant with the correct methods to audit and investigate perinatal mortality, researchers will have the true rate of unexplained stillbirths and will focus on the most needed research questions.

For example, a large Sydney teaching hospital that increased compliance with the guidelines effectively reduced the unexplained rate from 34 to 13%.

A Perinatal Bereavement Support Program in a large teaching hospital in Brisbane has also shown benefits for such educational programs for doctors and midwives in improving the uptake of the PSANZ guidelines, including appropriate bereavement care for parents.

Funding will enable a successful interactive teaching method for small groups to be rolled out across Australia.

Stillbirth is one of the most traumatic experiences a parent can endure. However, care received from doctors and midwives and other health professionals around the time of stillbirth has the potential to reduce the impact of this tragedy to families.

Unfortunately, there is insufficient time given to training of health care professionals in this area and many parents report receiving suboptimal bereavement care during their hospital stay.

Professor David Ellwood is the Chair of the Australia New Zealand Stillborn Association ANZSA and Vicki Flennady is a perinatal researcher of ANZSA and the Mater Mothers’ Research Centre, Brisbane.

ANZSA collaborates with its member organisations: Australian College of Midwives Incorporated (ACMI), Bonnie Babes Foundation, Mater Health Services, Perinatal Society of Australia and New Zealand (PSANZ), Royal Australian and New Zealand College of Obstetricians and Gynaecologist (RANZCOG), SIDS and Kids, Stillbirth and Neonatal Deaths Support (SANDS), SANDS New Zealand, Stillbirth Foundation Australia, and Women’s Hospitals Australasia (WAH).

For more information, see www.stillbirthalliance.org/anz
Consider the family

Liz Conway

The nursery is ready, the cot assembled. Little clothes are washed and folded ready for use. The ante-natal classes have been attended, the books read, the birth plan prepared.

Only the waiting is left—waiting for the first signs of labour, waiting to bring home a much anticipated and longed for baby. And then the worst—at a routine ante-natal visit no heartbeat can be heard. No movement. The baby is born at 40 weeks, perfect in every way—but lifeless.

To reach the final few weeks of pregnancy and give birth to a dead baby is a tragedy that parents shouldn’t have to endure. Unfortunately, this scenario is being played out on a daily basis across Australia.

The relative health of people in the general Australian community often means that people’s first glimpse of death is that of their baby. The cycle of life has gone in the wrong direction. Parents can often carry a sense of shame—why did their baby die when other parents who apparently didn’t look after themselves had a perfectly healthy baby?

The question of autopsy is often raised with parents. Autopsy is the ‘gold standard’ for investigation into stillbirth and for some parents an autopsy may give them an answer to the question of why. As difficult a topic it is to raise, autopsy should always be offered to parents. Parents rarely regret giving consent but often regret saying no.

Moving on

Family and friends may have difficulty understanding the depth of grief felt by parents and the length of time it takes for them to integrate the experience into their lives. The death of a baby is a life long event; when a baby dies, the future, the dreams the parents had for their baby, dies also.

Family and friends may want to quickly ‘fix’ the parents—suggesting immediate counselling, get the funeral over with to provide ‘closure’. Very often these measures are not for the parents but the family members or friends. Parents often find they are almost on their own after only a few weeks.

Two groups of people are often missed in the grieving process—fathers and surviving children. Fathers will often answer questions about their wife’s welfare without being offered the same consideration.

Children need to be given information about their sibling that is relevant to their age and maturity level. If included in the experience, children may gain a better understanding of life and come to know that nothing they did contributed to the death of their sibling. Seeing and holding the baby, attending the funeral and contributing to it are all activities that children can be comfortable with.

It is vital that people caring for children after the death of a sibling use the same language and explanations that the parents use when talking about the baby. Unhelpful explanations such as ‘God took the baby to heaven’, ‘the baby went to sleep’ can frighten children and make them wonder if God will do the same to them; if they go to sleep will they die too?

Grief is an emotionally and physically exhausting process and parents may feel unable at times to parent and nurture their surviving children as they would normally. This is a time for family and friends to provide good, practical support: taking the children out for a time to give the parents breathing space; providing meals; doing household chores.

Sands has been providing support for bereaved parents and their families for over 25 years. The philosophy of parents helping parents is one that has proven supportive for many Australian parents.

Liz Conway is the State Co-ordinator of Stillbirth and Neo-natal Death Support (SANDS) Q’ld.

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, normalising their adolescence was central to their feelings of ‘belonging’. As with their parents/carer, 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 substan-tially 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.

Acknowledgement:
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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).
Improving the hospital journey

Penny Gibson

This couldn’t be happening. There’s nothing really wrong with my child. It will be all right. These are the first initial reactions of parents who then find out that their beautiful baby is going to require weeks or months of hospitalisation, and years of ongoing care.


The parents feel powerless as their baby is transferred from hospital to hospital, specialist to specialist, health professional to allied health professional. They are confused. They are bamboozled by the medical language. They are exhausted and scared. Their own lives, relationships and families are at risk of disintegrating.

Empowering parents to help take their children and themselves through their harrowing journeys not only helps the parents, but the children—and the health professionals caring for them. There are better health outcomes when parents become an integral part of their child’s health care team.

In 2008, the Association for the Wellbeing of Children in Healthcare (AWCH) co-convened a conference with Children’s Hospitals Australasia to highlight the importance of advocating strongly for the health care needs of children and young people in Australia.

Four parents presented their thoughts on their journey through the hospital system. While acknowledging the effective medical treatment, the stories serve to remind health professionals that the best journey is one where the parents are recognised for their knowledge of the child, consulted with respect and supported to be part of the team.

The following excerpts are from the stories of ‘Fiona’ and ‘David’.

When Fiona was born in 2006, she was gorgeous, alert and happy but rapidly lost weight. The next four months were a nightmare where Fiona was eventually diagnosed with a genetic disorder that left her with multiple disabilities.

David was born in 2003 with contractures in his elbows and knees, dislocated hips, torticollis, hypotonia and tallipes. That was the start of months of tests that found many other problems, but no definitive diagnosis.

Communication and respect

All parents spoke of the need for health professionals to think before they speak and to avoid assumptions. ‘…the paediatrician arrived with three medical students, who stared at us with eager calmness and continued to try and stare into our brains and figure out their training on parent grief was correct.’

‘At the children’s hospital, another registrar set about asking us the same questions we had been asked a hundred times already.’

Sometimes the doctors have looked at us as if to say ‘I did not spend years at uni to be told by a parent what to do’.

‘An anaesthetist informed me the risk Fiona would die on his table (replacing a central line that had come out) was too high and he refused to do the consent with me…Somebody else completed the forms with me. I had no power, he had taken what little strength I had away. I was nothing, my baby was probably going to die and somehow it was all my fault. After 3½ hours she had a shiny new line; that man was wrong, he attempted an apology.’

‘Some doctors give a very negative view of what your child’s life will be like to ensure you fully understand how horrible it could turn out; they knock you down as far as you can go, then remind you that this little undiagnosed thing in the bed is your child.’

‘We met a metabolic geneticist who said Fiona would probably never walk, never talk; if she lived past one he couldn’t really tell us if she would have any quality of life…Thank goodness we had the best paediatrician in the world. She told us a diagnosis doesn’t change anything. So what if Fiona is disabled, she can still enjoy life. We needed to get on with treating our beautiful daughter, she was not a disorder, she was a child.

Knowledge is power

‘I sat around all day waiting to see doctors. They came in for a five minute consult, then I would forget everything they had said. They used big words that I started to learn fast, I got to know that, actually, I was the expert on my child. I learned that I could ask a doctor to come back if I didn’t understand something.’

‘In hospital knowledge is what makes you strong again, if you can articulate in ‘doctor language’ you get listened to.’

‘This is how our family began to feel in control again—in depth knowledge of her treatment, and that you can say no.’

Teamwork

‘We forged quite a powerful bond with David’s therapists and doctors—these people got to share our journey and see us at our best and worst and shared our massive high’s and dizzying lows.’

‘Sometimes medical staff realise that as parents of children with a chronic condition, we will actually know about our child, we know what treatments work better, we know the reason for each medication that has been prescribed and, most importantly, we are not neurotic parents.’

‘Our paediatrician was our daughter’s primary doctor and decision maker throughout our whole admission and still today. She would come and see us after hours or on weekends, to be sure we were both informed. We trusted her completely.’

‘Families in hospital need an advocate, co-ordinator and person to liaise with. They need a very experienced, reliable, dedicated doctor to run their child’s care, as they cannot do it themselves.’

Moving on

‘While everyone was so focused on David, no-one realised that my husband and I were falling apart, including us. We finally received counseling. I am still, today, very passionate about support for families, especially those with children who are extremely complex and/or do not fit into “the box.”’

‘We have faced many hurdles and challenges but now have a great support network of friends, family and hospital staff. We still don’t know about everything out there that could maybe be of service to us but we are slowly learning the ropes of living and coping with a child with a disability.’

CHF thanks AWCH for sharing these journeys.
Let’s evaluate the impact of consumer representation

Janney Wale

The Australian health system is increasingly evidence based and underpinned by evidence informed policy making. Yet evidence is often limited and cannot stand alone. Expertise and values judgement are an important part of informed decision making.

The role of consumer representatives in the decision-making process is becoming more recognised. However, as part of the evidence base, we need to evaluate the diverse roles that consumer representation plays in improving the safety and quality of our health care and optimising its benefits to consumers and their carers.

Within a patient-focussed healthcare system, this evidence base must measure, support and enhance consumer participation. In this way we can learn more about what is meant by consumer representation in Australia and how it is practised, identify good practices, and give recognition and acknowledgement of the impacts it is having by formally integrating it into strategic and operational planning (and performance indicators).

Consumer representatives bring their skills, experiences, knowledge and the views of a wider healthcare user group. In being involved in policy and service delivery development we are generally a minority component of a complex deliberative process. We work with differing roles, levels of involvement, settings, support and training, backgrounds and characteristics of the people involved, and group dynamics.

It is very difficult to judge any one individual on the outcomes of a discussion and decision making process. The impact of the contributions by consumer representatives varies. Sometimes the impact is not immediately obvious to the consumer representative or others. Different players may differ in their views on the impact. Furthermore, within a continuous process the point at which consumer representative involvement makes a difference may not be easy to identify; nor what exactly that difference was. Because of these multivariants, it is unlikely that one standard measure of the impact of consumer participation will suffice.

Therefore, rather than evaluating individual incidences of consumer representation, we must evaluate the process of consumer involvement. It is important that consumer participation adds value for all involved in the process; and that it is developed in partnership. And importantly, do the consumer representatives themselves feel they are able to make a contribution and give their input effectively within a clearly defined role and purpose of their involvement? For these reasons, consumers must help develop and implement this evaluation process.

Janney Wale is a Senior Consumer Representative who is active on several health committees and with the Cochrane Consumer Network.

Carers in the CALD community

Kelly Kljajic

Carers in the culturally and linguistically diverse (CALD) community endure many disadvantages, many related to cultural perceptions of caring and the difficulty in accessing information. As a nation, we need to address those difficulties so everyone has equitable access to care and services.

In the CALD community, the term ‘carer’ is not a term that is used easily, because the carer is often a family member who believes they are just doing their family duty by caring for their loved one. As they do not see themselves as anything special, they end up neglecting their own health needs.

CALD carers face the same financial issues that many carers face. Most are not aware that information and services are available to help them. Isolation and language difficulties limit their social input and their access to information and services. Many are reluctant to reach out even within their own cultural communities, due to feelings of shame for having a person that they must give their life tending to. As CALD carers grows older, their level of stress becomes greater as they feel guilty for not being able to offer their loved one the same kind of care they once did. They feel they have failed.

Their difficult situation is compounded by legislation. The Immigration Act is exempt from the Disability Discrimination Act and the current Social Security Policy states that new immigrants must wait ten years before being allowed to access the Disability Support Pension.

FECCA and the National Ethnic Disability Alliance have been working to change government policies and there has been some progress; for example, late last year the Immigration Minister announced an enquiry into these matters. However, more help for this group is needed. Research has already suggested it would be best to target each ethnic group separately to address carer issues.

Kelly Kljajic is the Disability Chairperson for the Federation of Ethnic Communities Council of Australia (FECCA), the peak body representing the culturally and linguistically diverse (CALD) community. She is also a member of the CHF Governing Committee.
Government jobs and rural sustainability

Jeff Wearne

It is important to realise that the state of rural health in Australia is inexorably linked to the much larger question of rural sustainability.

Too often those of us working to improve access to health services for people living in the bush have a blinkered view of the situation. We see a shortage of doctors in rural and remote regions for example, so we try to devise ways to boost their numbers. Because it is not in our direct purview, we tend to ignore the fact that there may also be a shortage of bankers, plumbers, sporting facilities, restaurants and schools in rural communities as well.

Rather than trying to confront rural and remote health issues head on, perhaps we would be better advised to try a less direct approach and look instead at fostering economically sustainable rural centres that offer both employment and lifestyle options so people, including health professionals, actually want to live there without having to be coaxed and cajoled into doing so.

Surely it would not be that hard; after all, rural centres already exist. Maybe some need sprucing up a bit here or there but they could offer a viable, attractive alternative to our increasingly overcrowded cities, as well as acting as regional inland hubs providing more convenient services (including health) to those people living in outlying areas.

With this in mind, it may well be time to reconsider decentralisation as a realistic policy option. Given they are major employers, federal and state governments could provide a much needed stimulus to our regional centres by simply relocating a portion of their workforce, particularly from relevant departments such as agriculture or fisheries. The resultant increase in population would provide an impetus for businesses and service providers to also set up shop and, before long, we have a vibrant, self-sustaining community able to attract health professionals and other service providers on its own merits.

Decentralisation using government employment is not a new concept. Naysayers will doubtless come up with a litany of problems, but nothing insurmountable compared to obvious benefits if the policy is successful.

The success of both Canberra and Albury Wodonga shows us that decentralisation can work well and surely it would be an advantage if our population centres consisted of something more than a few state capitals clinging precariously to the coastline.

Jeff Wearne is a Project officer at the Health Care Consumers of Rural and Remote Australia.

Call for step up and step-down facilities

Darlene Cox

The ACT is currently involved in large scale clinical redesign and health service planning to underpin an ambitious $1billion capital works program over the next decade. The Health Care Consumers’ Association of the ACT is closely involved, supporting consumer representatives on high level committees, holding consultations and commenting on documents. This as an opportunity to make our health system more consumer centred and overcome a number of longstanding problems.

One such problem is inadequate provision of sub-acute care, including rehabilitation, transition care, geriatric evaluation and management that can precede or follow hospital admission.

The National Health and Hospitals Reform Commission (NHHRC) acknowledged the importance of sub-acute care, describing it as ‘the glue that connects acute care provided in hospitals with community care provided in peoples homes’ and saying the limited provision of sub-acute care represents a significant missing link in the care continuum.1

Sub-acute facilities have usually been established to ease the burden of bed block, usually moving older patients to transitional care from (costly) hospital beds. They support consumers post discharge to regain daily living skills through personalised programs for up to two weeks before returning home.

Sub-acute care facilities can improve the transition process from hospital to home and embed linkage between the acute and community sectors of our health system. As one consumer said, ‘It will all boil down to getting people back on their feet (as it were!) and into their homes with the minimum of trauma’.

We would like to see further exploration of sub-acute care as an extension of primary health care, rather than acute care. The development of the ‘step up’ concept has been strongly supported by our members, especially those living with chronic conditions. It would enable consumers to receive a high level support in the community to keep them out of hospital.

This care could be provided by multidisciplinary teams, including a range of care assistants, and there is potential to work with general practitioners to include them in their supervision of clinical practice.

The NHHRC is to be commended for its call for targets to be set by June 2010 to increase the provision of sub-acute care. This is a good opportunity for the consumer movement to articulate what we need from sub-acute care so it meets our needs for step up and step down. We think the answer lies in reframing sub acute care as an extension of primary care rather than the traditional model tying it to hospitals.

Darlene Cox is the Executive Director of the Health Care Consumers’ Association of the ACT. For more on this topic, go to http://www.hcca.org.au/cms/index.php
