



Association for the Welfare of Child Health

Healthy Solutions for Children: Making the Right Choice

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The Past

I would like to begin with a brief history of the Association for the Welfare of Child Health (formerly the Association for the Welfare of Children in Hospital). AWCH was born in 1973 as a voluntary organisation consisting of both professional and non-professional people from all parts of Australia, interested in formulating and satisfying the non-medical needs of children and their families in hospital and health care. Currently we have membership in most states and territories, with the National Office and National Library services centred in New South Wales.

A Recommended Health Care Policy Relating to Children and Their Families setting out principles and practical guidelines was prepared by the Association and published in the Medical Journal of Australia as a special supplement in 1975. It was declared the official policy of the then Health Commission of New South Wales and the Australian Capital Territory and endorsed by the National Health and Medical Research Council. Over the years AWCH has produced a variety of holistic, family centred health care policies covering such topics as disabilities, play and general care (*Policy Relating to the Provision of Play in Hospitals, Policy Relating to the Care of the Child with Long Term Disability in Hospital, Policy on Maternity Services, Policy Relating to the Provision of Care of Children Undergoing Anaesthesia*).

The Australian Council on Health Care Standards (ACHS) incorporated the AWCH accreditation guidelines into their Evaluation and Quality Improvement Program (EQuIP) in 1998. The AWCH guidelines were the culmination of 3 years work and provide information on the standards of care for children and young people for all hospitals that have 5 or more paediatrics beds.

The Association at this time was funded federally by the Australian Department of Health under its Community Health Programme until 1986 when the funding was phased out. At this time we had to curtail our advocacy role for children and concentrate our endeavours on maintaining the AWCH audio-visual and reference library. Approaches were made to several institutions in an attempt to save the library,

and the structure offered by the University of Western Sydney guaranteed to maintain and continue the collection. Funding was then sought for the National Office and in a very rare situation the NSW government picked up the federal funding, which is a great compliment to and recognition of the work of AWCH. So since 1989 the NSW Department of Health, through the non-government organisation funding system has fully financed the national operation.

Over the years, AWCH has been the advocacy voice for children and their families in the health care system. Being outside the system, we are able to bring consumer pressure to elicit changes. AWCH has been instrumental in the introduction of 24 hour visiting by parents in hospitals; for the provision of parent accommodation; for the recognition of the importance of play in a child's recovery, the importance of a child and family friendly environment and the importance of family centred care.

AWCH provides a variety of services to the community through the National Office and AWCH Library and each branch also conduct their own particular programmes for local needs for example:

- The Hospital Familiarisation Programme which has been running in Western Australia for 20 years enables children to learn about medical equipment and aspects of hospitalisation in the safe and familiar environment of the classroom
- Friends of the Ward Scheme in the ACT and in New South Wales the AWCH Hospital Ward Grandparent Scheme both help children and families by providing a carer for the child or young person whose parent or carer can't be there during their hospital stay. The work of the 62 ward grandparent volunteers in NSW needs to be highly commended as in 2002-03 they put in the equivalent of 706 working days across 10 hospitals. A phenomenal achievement by these dedicated volunteers and the social workers who support them.

The emotional trauma of hospitalisation on young children is a very real thing. Our recent National President, Irene Hancock can still remember being admitted to hospital as a 5 year old with scarlet fever and her parents not being allowed to visit in the ward. Irene can still remember the beds and cots being turned around to face the meshed verandah and parents having to stand outside the mesh. Irene's dad had brought her some butter balls (for those of you who are old enough to remember them). He threw them over the meshing and told Irene to hide them from the nurse, under the pillow. This was also a time when there was restricted visiting by parents who could visit only in the afternoons on eg Wednesday, Saturday and Sunday. When the children were difficult to control after parents left, the wisdom of the day decided that children would be better off if parents did not visit at all and upset them! In those days health care staff took very good care of children's physical needs but were blissfully ignorant of their emotional non-medical needs.

Child and adolescent health care is rapidly changing and a growing range of specific needs are being identified. There are many different types of child and adolescent patients including long and short stay, those experiencing multiple admission or accident and emergency treatment, all with their own specific needs and issues. Emerging trends are towards such things as home-based hospital care, innovative pain and procedural management plans and the recognition of the vital role of the family in the health care team. Tele-medicine and the management of complex specialists issues from a remote location, and the increasing involvement of the child

and young person themselves in their own treatments are among the many complex factors changing the nature of child and adolescent health care in Australia. ⁽¹⁾

AWCH is currently involved with the NSW Health Greater Metropolitan Transition Taskforce in developing a coordinated approach for paediatric patients moving to adult health services. Much more work needs to be done but so far a framework document has been developed and is ready for use, funding for a Transition Project Manager and Coordinators who will assist in developing a coordinated approach to transition has been successfully sought and the issue has been raised in adult health care facilities by those who are experiencing young people with chronic illnesses and disabilities being transferred to an adult facility poor in resources and in many cases, expertise of those particular illnesses and disorders. It is a Pandora's box but with committed input from all those involved it will hopefully result in young people's health outcomes not being compromised or falling through the cracks.

Transition issues highlighted by the GMTT work identifies that the unique and specific health care needs of children and adolescents are often unrecognised in the wider health care system. The recent inquiry in Britain into the management of the care of children receiving complex cardiac surgical services at the Bristol Royal Infirmary between 1984 and 1995 highlighted *the need for patients to be the centre of the health care system, with their perspective included in the policies, planning and delivery of services at every level* ⁽²⁾ The report went on to say that the health care needs of children are very different from adults and this must be recognised.

Rapid technological advancement and fiscal constraints can override the focus on the child, adolescent and their family and how they manage illness with the least impact to their whole lives. Disturbing trends towards reintegrating child and adult health care facilities are emerging. Accommodating children and adults together on the same hospital ward has been a common complaint which has kept AWCH busy over the last few years. In October 2002 AWCH held a roundtable conference in Sydney to discuss solving the issue of children and adults being admitted to the same hospital ward in NSW. Some of the problems with this practice raised were:

- safety of children, as outlined in the *Children and Young Persons (Care & Protection Act) 1998* being contravened
- unmet needs of children and young people
- coordinated approach needed
- review *NSW Health Guidelines for the Hospitalisation of Children and Young People 1998*
- Health Department regulations ignored when building/refurbishing health facilities
- Caring for adults in children's wards and children in adult wards particularly in mental health units
- unvetted adult patients into children's wards – unlike health staff who are required to undergo criminal record checks and prohibited employment declarations
- Poor modelling for future clinicians who observe this practice and think it is acceptable
- Guidelines ignored because they are not policy
- After hours adult admissions to children's wards is a constant practice
- Appropriate levels of staffing

- quality care issues - incorporating skills and competencies of paediatric trained staff nursing adult patients and adult trained staff nursing children

Through media releases and discussions with various child health organisations and AWCH members it is clear this practice has been happening Australia wide. With an albeit slow but growing recognition by adult as well as paediatric services of the particular needs of children and young people AWCH hopes that this practice will be seen as not in the best interests of children, their families or indeed the health care service which should be putting the patient at the centre of their focus - if they are wanting to provide a first class service with safety as a high priority.

The need for increasing cultural awareness and sensitivity of health care services to the distinct needs of Aboriginal and Torres Strait islander families, as well as families from a culturally and linguistically diverse background has also been highlighted. A recent trip by the AWCH National Liaison Officer to some supported playgroups running under the Families First Initiative in Western Sydney highlighted the need for translated materials so that the CALD families could benefit from AWCH services and support. Also the unique support needs of children and adolescents being treated for long periods away from their home and family are a constant challenge for health care workers.

In 1993 AWCH changed its name from 'the Association for the Welfare of Children in Hospital' to 'Association for the Welfare of Child Health'. This reflected the understanding that child health is not just a matter of attending hospital and getting better but that there are a whole range of determinants underpinning child health and the well-being of children. This has been reflected in previous conferences (Children on the Margin in 2001, Healthy Justice for Children in 2002) which looked at the health care needs of marginalised children and young people and the impact of the justice system on children and families. One of our keynote speakers at the 2001 conference was the newly appointed human rights commissioner Dr Sev Ozdowski. AWCH had expressed concern about the health and emotional wellbeing of children in detention centres and we asked the commissioner to present a paper on this issue. That AWCH conference paper was one of the catalysts for the *National Inquiry into Children in Immigration Detention* which is due to be tabled and reported on in parliament this year.

The Future

So what does the future hold for AWCH? In the same way that hospitals have had to 'reach out' towards the community to provide appropriate health care in the 21st century and take on a role of 'health centre' with a component of facilitating health promotion and early intervention, so AWCH is having to look past hospitals as the only place where child health issues are addressed. An example of this is the concern our AWCH Patron Dr John Yu has about the state of school toilets and their impact on child health.

Indeed on a recent visit to a Sydney school, the AWCH National Liaison Officer was shocked to find out that the school has a policy of 'a 2 people toilet policy' where no one in the school including adults goes to the toilet on their own. There is obviously much work to be done to make school toilets safe and hygienic for children. In the

same way when AWCH canvassed its members earlier this year to ask what they might wish to have in the AWCH 2005 Conference the top picks were:

- Health Promoting Schools and the education system and child health issues
- Crossover between law, ethics, health, education and child health issues
- Media impact on child health
- Drug/alcohol/mental illness of parent/s and the impact on child health
- Childhood Obesity
- Impact on children of integration of children with disabilities/chronic illness into the school system or into childcare
- Role of hospital and health services

The health care system is beginning to recognise the value of early intervention, health promotion and the importance of social determinants in health, which is exactly behind the philosophy that AWCH has been espousing for over 30 years: aiming to ensure that the emotional and social needs of children and young people are recognised and met within hospitals and the health care system. Working collaboratively across sectors and thinking about the 'whole' in child health as well as maintaining appropriate care for hospitalised children will be an AWCH focus for some time to come. The AWCH advocacy role will increase and AWCH is keen to work collaboratively with other organisations such as Children's Hospital Australasia and the Confederation of Paediatric and Child Health Nurses as a more effective and powerful way of ensuring that child health needs are met and taken seriously.

On a less positive note you probably won't be surprised to learn that funding has become an issue for AWCH just recently. With the administration of the AWCH Library and the National Office rent free accommodation being terminated by the University of Western Sydney during 2003, AWCH has been faced with the need to provide accommodation for both the AWCH Library resources and the National Office and the need to find funding for a librarian position is paramount. Temporary arrangements have been made for 2004 which allow the work of AWCH to continue but a permanent solution, particularly concerning the AWCH Library has yet to be found.

AWCH, like many organisations, is having to look at new ways of doing its work and the capacity of the organisational structure to be effective and so in 2004, AWCH will undertake a review of its structure and what it wants to achieve in the next 5 years and how it is going to go about its work. In the meantime, AWCH will continue to field enquiries from parents about their experiences of the health care system; provide literature, information and advocacy support to health professionals; put families in touch with support groups; and offer its expertise and knowledge of the psychosocial needs of children and young people to the health systems Australia wide.

Reflecting on the past does give us inspiration for the future and what can be achieved. I would like to finish on a happy note by showing a short video, which was made by Dr. Anne Johnson from South Australia. To enjoy it fully, please listen carefully to the interaction and conversation in the early part of *Where have we been. Where are we going* – you will realise by its end that **we are making a difference for children.**

Thankyou.

References:

- (1) *Children and Young People - The AWCH Perspective*, Irene Hancock, RN, RM, Grad. Dip. Law, Grad. Dip. H.S.M., DNE, National President Australian Association for the Welfare of Child Health (AWCH), 7th International Paediatric and Child Health Nurses Conference "Caring for Kids" Sydney, May 2002
- (2) The Inquiry into the Management of Care of children Receiving Complex Heart Surgery at the Bristol Royal Infirmary. Final Report. *Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 –1995*. Command Paper: CM 5207
http://www.bristol-inquiry.org.uk/final_report/index.htm