



# Co-operative Newsletter

June 2008

Welcome to the Co-operative Newsletter for June 2008. The Co-operative has been successful in obtaining additional funding through DADHC until June 2009 and will be working with the Department in seeking further funding opportunities to enable it to continue its work in the Macarthur communities.

The Co-operative is represented at a number of community events, local and regional forums, which provided the opportunity to promote the needs of families, how the Co-operative can benefit both families and the services they use, and to generally raise the awareness within the community of disability issues. A growing number of families are contacting the Co-operative for a range of information, advice and support and through our network of partner services we are able to generally assist them.

Plenty seems to be happening at both the State and Federal levels at the moment concerning disabilities and carer issues and I endeavour to convey information about this to families and services via email and mail outs, and when people contact me. It seems these days it is not the lack of information that's the problem but being able to access it, especially if you are not on or have access to the Internet

The newsletter can now be found on our website [www.fip.org.au](http://www.fip.org.au) under the News page. If you have access to the Internet and do not need to receive a paper copy of the Newsletter, please let me know and we can both help the environment

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## ***Disclaimer***

This newsletter is provided for information and awareness purposes only. People should make their own enquires and judgment concerning any information, service or product contained within. The views expressed on this newsletter are not necessarily those of the FIP Co-operative Board, its staff or its members.

## **Co-operative News**

### **Good News Week for the Co-operative**

At a meeting in early May the Board met with senior officers from the regional office of DADHC who surprised members with an offer of a one-off grant. This will enable the Community Development Program to continue for an additional 10 months until June 2009 after Health funding is used up in August. DADHC have indicated that the offer was in recognition of the work that the Co-operative has been doing in the Macarthur over recent years concerning a number of issues facing people who have a disability and their families.

Final contractual details are currently being finalised to enable our priorities with DADHC to commence from September. They will embrace the priorities that the Co-operative has been working on under funding from NSW Health; with a bit more of a slant towards community awareness and ensuring families/carers are aware of their options in supporting their family member.

The Co-operative would like to thank the Department for their initiative in providing funding, and to our many families and supporters who advocated on our behalf to local Members of Parliament and the Minister for Disabilities. Your support did make a difference we believe and was appreciated.

The Co-operative also thanks the efforts of our local MP's in supporting our service and therefore local families and people who have a disability.

### **Co-operative's Website**

Our site continues to be access by a wide range of people and is becoming an essential way of communicating with a wider range of families and people looking for information and support. It is a good way of referring people to find out more about the Co-operative and gives them links to other services and information.

The site is updated each month with new information and we welcome your feedback on how it could be improved or what other information you would like on it.

### **Carer education and training**

Following the success of the Advocacy Workshops, a partnership is being developed with the MDS Training Centre to provide a range of opportunities for carers and family members to increase their knowledge and skills in their caring role.

The partnership will ensure carers/families have access to locally based education and training that can be used by people in their day-to-day lives or for an employment pathway if they follow a competency based learning structure of learning.

The Co-operative would like to hear of people's needs in terms of carer education and training so a program can be built around them. Give the Coordinator a call or an email with your ideas.

### **Membership now Due**

Membership of the Co-operative is now open for the year 2008/2009 with a fee of \$5 required to be paid by the end of July. Renewal forms have been sent out to all existing Co-operative members, and people can become members by either contacting the Coordinator or downloading a membership form off our web.

Membership of the Co-operative is open to all families with a member who has a disability, local service professionals and interested community members. Becoming a member provides you with the benefits of accessing the resources of the Co-operative, participation in its decision making processes and showing your support of the Co-operative's ideals and services.

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## **Through the Maze 2008 Edition**

The Association for Children with a disability NSW has provided the Co-operative with a number of copies of this invaluable resource for families who may have had their child diagnosed with a disability. It has a wealth of information and contacts in a wide range of areas that families face in raising their child, both now and later in life.

First developed and published some thirteen years ago this edition has been funded through the Department of Ageing Disabilities and Home Care and is a great handbook for all families and services working in the disability field. If you would like a FREE copy from the Co-operative just contact the Coordinator to enable one to be posted out. Alternatively you can go to [www.acdnsw.org.au](http://www.acdnsw.org.au) web site and download it in an electronic form.

Congratulations to all the families and people involved in producing Through the Maze, it will be an invaluable resource for all families.

## **National Call to Action**

The Australian Advisory Board on Autism Spectrum Disorders represents the views of its members in identifying and addressing the needs of people with an autism spectrum disorder (ASD) in the Australian community. The National Call to Action is the result of a collaborative approach that identified the imperatives for the autism community. And was released at a Parliamentary breakfast in Canberra where Federal MP's were provided information and made aware of the growing need within their electorates.

### **The Call to Action States:**

We appeal to both national and state policy makers for a whole of government approach to ensure effective resourcing and structuring of future service delivery. Key areas are:

#### **1. Access to Diagnosis**

- A national experience of no more than 3 months waiting time for a diagnosis;

- A national benchmark for a multi-disciplinary diagnostic team responsible for the process of diagnosis; and
- Medicare rebates are available for diagnosis.

## **2. Official Reporting of Autism Spectrum Disorders**

- That the autism spectrum disorder be included on state and national data registers such as the Australian Bureau of Statistics (ABS), Centrelink and the Australian Institute of Health and Welfare (AIHW). This will be achieved by:
- The development of a national Register of Autism Spectrum Disorders, that includes autism or autistic disorder, atypical autism and Asperger's disorder; and
- Government action to include autism spectrum disorders on registers such as the ABS and AIHW.

## **3. Early Intervention for Young Children (aged 0 – 6 years)**

- Every child has access to a minimum 20 hours of support per week;
- There is a waiting period of no more than 3 months between diagnosis and service provision; and
- Equitable access is provided for all children with special consideration given to families in rural and remote regions.

## **4. Education**

- That every child has access to an appropriate educational service appropriate to his/her needs in compliance with the federal Disability Discrimination Act (Education Standards,2005);
- That educational services are based on sound evidence and quality indicators;
- That all government and non-government educational sectors provide educational services appropriate to the needs of children with an ASD;
- That educational services be responsive to all children across the autism spectrum, including children with Asperger's disorder who are frequently not diagnosed until they are at school;
- That there should be a range of educational services for children with an ASD from specialised autism-specific programs to mainstream programs with appropriate adjustments;
- That there be a waiting period of no more than six months between application for an educational service and enrolment; and
- That educational programs and services address the needs of speech, social skills, behaviour and sensory issues and family support.

## **5. Family Support, Assistance and Respite**

- That families have access to a range of models for support and respite;
- That the models of support are flexible and responsive to the needs of families;
- That specific services be targeted at meeting the needs of siblings of a person with ASD;
- That specialised services be available for people with exceptional needs;
- That generic services be adequately informed and educated to provide appropriate support; and
- That ageing carers of adults with ASD have access to flexible and affordable short term respite support for their son or daughter as required.

## **6. Services to Adults with an Autism Spectrum Disorder**

- That adults with ASD receive services and support from professionals with appropriate training in autism and related needs;
- That adults with ASD be given every opportunity to have a full and rewarding life by being as much part of the community as they possibly can be;
- That adults with ASD be given every opportunity to be part of the work force;
- That specialised models for long and short term accommodation services be designed to meet the specific needs of adults with ASD; and
- That adults with ASD who have a dual diagnosis have access to community, health, mental health and related services and support as required.

## **7. Research**

We call for Australian research program into the treatment/intervention and aetiology of autism spectrum disorders

For more information on the Advisory Board's National Call to Action, please contact Adrian Ford Chairperson (02) 8977 8300

Source: A4 Email alert May 2008

## **Friends of the UWS School of Medicine**

The Co-operative, along with a number of other local services and community members have become Friends of the School of Medicine and are actively involved in the development of our future doctors.

Currently has Year 1 and 2 students are studying at the newly opened Medical School facility on the Campbelltown UWS Campus. A very impressive facility housing state of the art learning spaces and research facilities and well worth a drive by view if you are in the area. Students are also gaining onsite experience in the Clinical Schools at Campbelltown and Blacktown Hospitals.

When the School has its full complement of students across the five years of the Undergraduate course, there will be over 500 students and some 120 teaching and administration staff involved.

From 2009 Year 3 students will be undertaking 12 weeks of Medicine in Context where they will be placed with local community services “to provide and intensive introduction to the social and cultural contexts of health and disease through community immersion”. What this means is they will be given practical experience of working with a local doctor and a community service that works with disadvantaged groups living in the Greater Western Sydney region.

A number of disability focus services have agreed to take on medical students, giving them an insight into services provided, barriers that people who have a disability and their carers encounter and the important role doctors can play in meeting their health needs. The Co-operative has been a catalyst for the School of Medicine engaging with services and we will continue to advocate for the inclusion of disability issues in all areas of student study and research.

### **Out Patient Clinics**

An important impact of the progression of the School of Medicine has been the commencement of a range of clinics run by Professors and Doctors engaged by the school. The clinics will provide patients with access to major medical services that have previously not been available to the Macarthur community and new teaching opportunities for medical students and junior medical officers” Mr Wallace of the SSW Area Health Service said.

Senior Medical Physician, Professor Brad Frankum, said the changes are a positive boost for both hospitals and an enormous benefit for the residents of Camden with an increase in access to specialists and expansion of current outpatient services. “The University Medical Clinics will include specialist care in allergies, respiratory medicine and hypertension and diabetes in pregnancy,” Professor Frankum said.

“The Clinics are an opportunity for staff to do broader research and it will help develop Camden Hospital as a centre for excellence in complex patient care.” the media release provided by the Area Health Service stated.

### **Kites 4 Kids Family Fun Day**

Planning is underway for this annual event that celebrates the abilities of all children and aims to increase awareness of Macarthur based Early Childhood Intervention services. It’s a great day out with plenty of FREE activities for all the family.

Why not come along, decorate a kite and see how your family can make it fly (or not). Put it into your diary or calendar now so you do not miss out.

**Saturday 23<sup>rd</sup> August 11 am to 2 pm at Koshigaya Park in Campbelltown**

### **Down Syndrome Support Group**

For parents/carers of children aged 0 – 6 years offering an informal and relaxed get-together where you can gain information and support from other parents/carers. It is run by parents for parents with a morning tea held on Thursdays, 10 am at Sharecare in Green Valley Road Heckenberg, a suburb of Liverpool.

On the 26<sup>th</sup> June they have a guest speaker on hearing and obstructive sleep apnoea – Jill O’Connor, but most months it is a time to hear from other parents/carers. All interested people are welcome along with their baby or child, with families from the Macarthur area already attending.

**Melissa Cotterill can be contacted on 9825 1973 or mob 0418 162 544.**

### **WTIM - Working together in Minto**

The Co-operative is involved with a number of other agencies and community representatives on the Older People and Disabilities Working Group, which provides information, ideas and advice to the Department of Housing's Minto Renewal project.

As the name says, it provides an opportunity for local people and services to work together to ensure the renewal of the Minto area is in line with resident's expectations and that the needs of older people, people who have a disability and their carer's are heard. Through the Working group a number of residents ideas have been developed and implemented including:

- Information cards
- Senior Week Activities
- Identification of Access issues at Minto Mall
- Advocating of the use of Universal Design principles in housing and community spaces
- Outreach services by Community Health

This is another example of the way Co-operative works in partnership with people and services in Macarthur and encourages any families living in Minto to make contact with the Co-operative to ensure their needs are being included.

### **TAD NSW - *Freedom Wheels***

The *FREEDOM WHEELS* customised bike program modifies standard push bikes to give a new kind of independence to children with disabilities by allowing them to ride a bike for the first time. With the help of a highly skilled and innovative team of therapists, engineers and volunteers at Technical Aid for the Disabled (TAD), children with disabilities can now enjoy mobility and a form of recreation previously unavailable to them.

TAD creates highly customised bikes at our popular bike clinics where clients are examined and assessed. The bikes are then modified to suit the particular needs of each child. [Click here](#) to download the Freedom Wheels brochure off the TAD NSW website, [www.tadnsw.org.au](http://www.tadnsw.org.au)

Source: TSCNSW Newsletter

### **The Dilly Wanderer**

#### **St Anthony's Family Care Mobile Activity & Community Information Service in partnership with Wollondilly Shire Council**

The Dilly Wanderer provides a FREE mobile activity, community information and development service for residents by providing information and access to services and activities across the Wollondilly Shire. Supported by a Program Coordinator and a Childcare Worker the service provides an environment where parents and caregivers of young children can socialize and gain information and support about a range of issues including:

- Access to outreach components of local and regional community service providers eg Family Support, Health workers, Youth Services and more
- Parenting support and mentoring
- social skills development for children and adults including first time parents and isolated families
- Health issues
- Government services, and
- local community events and services

The Dilly Wanderer works in close partnership with a range of local services and regularly has guest visitors attend the site to provide information and talk to families about relevant issues or upcoming events. The mobile activities offered at the nine locations across the shire on a monthly basis cater for young children, aged to 13 years.

All children in attendance must be accompanied by a parent or adult caregiver. The child's safety and behaviour remains the responsibility of the adult at all times. An up to date schedule of when the Dilly Wanderer will be in your area can be obtained by phoning Wollondilly Council on 4677 1100.

### **Wollondilly Community Strategic Plan 2030**

Have you ever wanted to have your say about Community and Council issues? Have you ever wanted a chance to interact with other community members about what is important in your town? You can do this while in the comfort of your own home or work, or on the train. Wollondilly Shire Council has a new on-line community engagement tool that gives you the opportunity to make a difference and share your ideas.

Wollondilly Shire Council wants to know what you think about Wollondilly and has an interactive web service called *Bang the Table*. It provides residents with an opportunity to comment and make suggestions about certain important issues or documents that are currently in the spotlight.

Council is aware that it is difficult for people who work outside our Shire or have accessibility issues to attend our Community Forums, view exhibitions and come to information sessions. *Bang the Table* is a way that all interested members of the Shire can see what is happening at Council and in the Community. "This service is provided by us to cement our commitment to community engagement. Your constructive suggestions are important to us and will help us to build a stronger community," says Wollondilly Mayor Cr Judith Hannan.

Currently Council has the Community Strategic Plan 2030 on exhibition and on the *Bang the Table* web site. You can read the document and be involved in online discussions about the Plan on the same internet page. Just logon to [www.bangthetable.com.au/wollondillycommunityplan](http://www.bangthetable.com.au/wollondillycommunityplan) and have a look and have your say.

**Ally Dench Manager - Community Services 4677 1108** [ally.dench@wollondilly.nsw.gov.au](mailto:ally.dench@wollondilly.nsw.gov.au)

## Disability Services Ministers' Conference

### Media Release 30 May 2008

People with disabilities, their families and carers will benefit from a \$1.9 billion boost in funding under a new agreement reached today at a meeting of Disability Ministers in Sydney.

State and Territory Disability Ministers agreed to deliver \$900 million in funding, on top of the Australian Government's \$1 billion commitment. This is a major step forward for Australia's disability system, which has been hamstrung for years by buck-passing and a culture of reactive crisis management, to the detriment of those it is meant to support.

The \$1.9 billion is expected to provide around 2,300 in-home support places, 2,300 supported accommodation places, 9,900 individual support packages and 10,000 much needed respite places, in a range of forms, across Australia.

While today's agreement marks a valuable and strong first step in addressing unmet need, Ministers acknowledged more needs to be done. All governments agreed that access to services would be provided on a case-based approach, to ensure people with disability receive appropriate services when needed.

Ministers also agreed to deliver 309 new supported accommodation places through the \$100 million in capital announced by the Prime Minister on 4<sup>th</sup> May which will start to be rolled out immediately.

In total, there will be more than 24,500 places that will begin to ease the anxiety of people with disabilities, their families and carers, many of whom have been waiting too long for support. The Australian Institute of Health and Welfare has estimated that the total unmet demand for accommodation support and respite services for people with disabilities, their families and carers is around 23,800.

Ministers also agreed to bring about improvements in the areas of advocacy, measurement of unmet need; innovative policy development, quality assurance; research and national consistency for the provision of aids and equipment. With an emphasis on working smarter, these improvements will be outcome focused, driven by research, informed by feedback from people with disability and carers and framed in an environment of renewed co-operation between jurisdictions.

Work will also commence on addressing the critical issue of workforce shortages facing the disability services sector across the country. Ministers reaffirmed their commitment to work to improve outcomes for children and adults with autism, and to continue important initiatives to provide young people with disabilities in residential aged care with more appropriate accommodation.

State and Territory Ministers will also work in partnership with the Australian Government on the development of a National Disability Strategy, which will deliver a whole-of-government, whole-of-life approach to disability planning, in consultation with people with disability, carers and other stakeholders in the disability sector. The Strategy will also seek input from groups within the disability community, such as carers, women, Indigenous Australians, migrants, and people in remote and regional Australia are also represented in policy planning.

Disability Ministers agreed that \$51 million, in existing contracts with respite services, will be transferred from the Australian Government to the State and Territory Governments from 1 July 2008. These agreements complement the existing \$324 million that will be provided under the current CSTDA, which was recently extended in line with all other specific purpose payments, until 31 December 2008.

The Governments will continue to work collaboratively through the Community and Disability Services Ministers' Conference to develop the new disability services agreement, which will be in place from 1 January 2009.

Today's meeting made further progress on outcome measures for the disability services agreement. A further report will be provided to the next meeting of the Council of Australian Governments. Further negotiations will continue on other aspects of the new agreement as part of the Commonwealth – State reform agenda. Today's successful agreements are yet another example of how Australians benefit when all governments work together.

## Statistics, Statistics and just plain lies

That's the old saying about all the figures we hear about in our modern world. It is easy to make any set of figures to say something we want it to mean, especially when those marketing people and politicians get hold of them.

The Survey of Ageing Disability and Carers is the main source of population-based data for the disability sector and is carried out nationally every six years. The last one was in 2006 so next year another survey is due with results available in September 2010. This is in addition to the questions asked in the recent ABS Census on disabilities and carers.

The Australian Bureau of Statistics (ABS) is currently consulting national and state organisations and other stakeholders on how to improve the survey. Some of the possible and significant changes are:

- Increase the sample of the survey, doubling it to around 36,000 households. This will reduce the error factor in such a survey and improve the reliability of inter-state and rural-urban comparisons.
- Additional detail on the current and projected need for services - over 50% of the 2003 survey respondents with a profound core activity limitation reporting needs were only partly met or not met at all. Estimates of the need of services however remain problematic and need to be better measured through the survey and other means.
- More frequent updates on workforce participation and employment rates for people who have a disability and carers. Follow up in between surveys is needed to provide more realistic data.

Source NDS E-newsletter May 2008

## Comment

Statistics are very important for governments to set levels of funding and developing services in areas of need. Local governments use them to inform them about access and development planning and services use them to advocate for people's needs and when tendering for funding.

So it is important that we collect the right statistics and tell the story as it really is so people do not distort them, underestimate the level of need within our family or community, and create a more inclusive and just society for everyone.

A summary of the 2003 Survey can be found at [www.abs.gov.au](http://www.abs.gov.au)