

Families for Change



ALL THAT GLITTERS IS NOT GOLD!

Promoting and defending the rights and interests of people with a developmental disability.

Summer 2004

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family
ADVOCACY

In these times, it is rare to see a current affairs story about people with disability which doesn't paint a negative picture – suffering, pitiful, afflicted, dependent and receivers rather than givers. How many people saw the 7.30 Report on ABC in October? Some people have said that the piece on an easier way for genetic differences to be identified even earlier in pregnancy stopped them in their tracks. The treatment the subject was given was as different as it was captivating. For the first time, hard questions were asked about the damaging effect of pre-natal testing on people with disability, on families and on all of us as a community. How great to see a challenge to the accepted (medical and broader cultural) view about children and adults who have Down Syndrome with portrayals of positive roles – friend, peer student in a regular class, gifted, contributing, loved and welcome. The program also challenged the accepted so-called wisdom that such technology is doing nothing more than enabling personal choice.

Media stories that challenge the community to think differently and positively, and that add to the debate, are rare. That's what makes them gems. More common are the baubles and trinkets – attractive, even dazzling, but without substance - and we have had a lot of those on offer from the powers-that-be in the last year.

At the beginning of a new year, we have looked back over 2003 to recall some of the gems – those things that will really make a difference. The newsletter also identifies the trinkets on offer, those things that were eye-catching but which only served as a distraction. The newsletter also has a few ideas about sorting the treasure from the trash in 2004.

Gems from 2003

★The Department of Ageing, Disability & Home Care announced that they would increase the number of Local Support Co-ordinators in regional areas of NSW. This is very welcome news. Family Advocacy continues to make strong representations about the need to ensure that Local Support Co-ordinators do not become yet another part of the “disability service system”. Rather their role, assisting individuals and families build community connections and a range of support, should be strongly safeguarded.

★The conference “Gathering the Wisdom” in Brisbane in April – a treasure chest of inspiration from people with disability, families and others involved in social change. The organisers, the Community Resource Unit, are now finalising a book of the presentations.

★The on-going and larger debate about true “family-governed” supports and what it takes to put the concept into practice.

*“I have enrolled my son
in regular school –
he is coming out of the support class.
When the school said that he
‘wasn't ready’,
I had an answer. I don't feel sorry for
him or myself any more. I feel liberated
and see everything differently now.
I know it will be hard work, but it
will be worthwhile.”*

Feedback from a parent from southern
New South Wales, after an advocacy workshop
on education.



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Advocacy incorporates the notion of:
Standing beside people who are vulnerable to exclusion
Being in contradiction to the various forces that lead to social devaluation and exclusion

"It is so important that organisations like Family Advocacy touch people who are angry and show that the energy spent on negative things is just wasted and futile. It is a hard lesson to learn but you are teaching that, both directly and indirectly."



Feedback from a parent who attended a recent workshop.



Trinkets from 2003

In the last year, there have been lots of things to catch the eye – regionalisation, re-structure and reform. The Government has spent huge amounts of money on Departmental amalgamations and regionalisation with both the Department of Ageing, Disability & Home Care (DADHC) and the Department of Education and Training (DET) going through major restructures. While it is argued that, in the longer term, the changes will reap benefits, people with disability and families have heard this very same argument numerous times over many, many years.

One of the features of re-structures is that, while they generate lots of "busyness", few decisions are made.

– Meetings are very difficult to arrange or, when they are finally organised, the people you see are in acting positions and can't make a decision.

– You can even find that, by the time the meeting date has arrived, the person with whom you initially made it has moved on to another job, another Department, another State or even country!

– Personal assistants need a degree in diary co-ordination! Then it could be that the meeting gets cancelled with a day's notice.

– If the meeting does go ahead, you may find that the issue you were going to see them about has been overtaken by others which were not even on the horizon when you began your quest.

It is easy to lose your passion at times of re-structure; resilience is the best safeguard – focus on things that you can change, strengthen yourself and be ready to bounce back!

■ The State Budget handed down in June produced very little increased funding for actual on-the-ground support but large

amounts for bureaucratic data bases and client management systems.

■ The State Election in March produced little by way of policy gems. The Government and the huge Department (DADHC) seemed to lurch from crisis to crisis. How they expect people with disability and parents to put any kind of trust in them is difficult to imagine.

■ 800 families who were promised a move to long-term support arrangements through the Service Access System were shocked to be told that their interim funding was to be cut off. Now they have neither short-term nor long-term support.

■ The Government re-stated its commitment to the closure of institutions but promises made to parents about new accommodation and timelines were not kept.

■ DADHC eventually refused to allocate funds to a proposal which would focus on developing more effective and inclusive ways of supporting individuals with disability inferring that a regionalised Department will have, in itself, the capacity to bring about personalised support for people with disability and families.

■ DET looked at ways to better support students with autism but then embarked on a policy of increasing segregation by building more support units for these students.

■ The Adult Training, Learning and Support Service (ATLAS) program, seemingly designed to provide post-school vocational support, employment and training for school leavers, instigated a new system of assessing a large group of people as "Code 01 and 02" which translates as "having the potential to access community-based recreation, leisure or community access options" signalling very low expectations about the future for a significant number of people.

"A. has been accepted into the primary school mainstream. We prepared a booklet about her which looks fabulous with photos from the preschool showing her busy at tasks and surrounded by her friends. A. gets to go to school with the friends she has made at preschool, not to forget being included from Day 1 at school."

Extract from feedback from a Local Support Co-ordinator.



The negotiations between the State and Commonwealth Governments about the Commonwealth/State/Territory Disability Agreement (CSTDA) bring very little real funding to NSW from the Commonwealth.

And so to 2004

As a parent, at a personal level, you may have to become a gemologist! Using your metal detector, you may be able to:

→ find a real ally to your quest for inclusion – maybe a family member, or a friend who will actually join you in developing and putting into reality your vision for a real life for your child or adult with a developmental disability.

→ discover those gems in the professions – a principal who actually understands, is committed to and "does" inclusion; a worker who understands the importance of relationships in the life of a person with disability; a manager who is prepared to think "outside the box"; a neighbour who looks forward to their (non-disabled) children being in the same class as your child with a disability.

→ actively search for inspiration from other families who are challenging the status quo and getting results.

For our part, Family Advocacy will continue to look for the windows of opportunity. We will be on the road again around the State bringing new ideas, practical ways of achieving change, and inspiration from other parents and family members (see Coming Events p.6).

We will continue to try to sort through the gems and trinkets of re-structure and reform in order to channel more resources into the system and to ensure that it is spent in ways which strengthen positive roles for people with disability in our society.

The Contribution Of Service Workers In Getting The Relationship “Right” Between People With Disabilities And Their Communities

Michael Kendrick sets out some important ways in which the small efforts of ordinary members of the community can be encouraged by direct support workers, who have a role at the interface between the local community and some of its vulnerable members.

It is not always obvious to us that our personal efforts in our communities make all that much difference on any given day. Nevertheless when we step back and view it over a longer period of time there are often signs that give encouragement. This is the case with what may seem the rather ‘ordinary’ efforts of everyday service workers in helping people with disabilities to be more fully a part of their communities and to fully enjoy it. The very simplicity of these contributions often masks their potential profundity and importance. That is why it is important to give them the recognition they deserve. What follows are some examples of how such contributions are made.

Help people meet people. Loneliness and isolation can be terrible burdens and it is always a welcome change to meet and spend time with others. However, meeting new people is not always easy, and even a small amount of thoughtful assistance can go a long way towards making the process an easier one. It is also true that the more a person gets experience with doing this, the more relaxed and natural it can become. Many a service worker has found a way to be helpful in bringing people together.

Keep community encounters comfortable. Underneath the surface of our lives within community there are many fears, doubts, anxieties and apprehensions that can inhibit the ways in which people simply ‘are’ with each other. For example, many people with disabilities encounter a

certain discomfort in those who are not sure how to act, or who are uneasy being in the presence of people whose appearance or disability is a difficulty for them. It is interesting that despite the fact things may start this way, people can quite quickly shed such fears and inhibitions as they come to realize that people are just people. Anyone who helps build feelings of comfort between others is making a useful contribution and often this may be a contribution that support staff can make.

Help people see the potential of people with disabilities. It is a common problem that most people underestimate the capacities of people with disabilities to play a larger role in community life. This is not easily overcome but it will eventually yield to the efforts of people with disabilities, their staff and other supporters to open people’s minds and to change their ways. Since these changes often come in small increments it may not always seem like a ‘breakthrough’, but looking back it can be seen that indeed it was one. Often it is just be a matter of persevering until we get a chance to show people what is really possible when someone is given a chance and thoughtful support. Many support workers would do well to be recognized as potential ‘mind changers’ and ‘opportunity makers’.

Help non-disabled people to see their own potential in relation to people with disabilities. It may not be clear to many non-disabled people that they have a contribution to make that would be welcomed and appreciated. Some people

may be bound up with their own misleading stereotypes about themselves and thus not act in ways that would be helpful, but many people are simply unsure of themselves and may benefit from a bit of expanded vision and steady encouragement to explore the kinds of roles and contributions they can make to benefit people with disabilities. Their contributions could spill into any conceivable role in life that they could either personally play, or support being played by people with disabilities. These roles could include friend, neighbour, employer, club member, colleague, spouse, business partner, mentor, ally or many other roles. There is no ‘automatic’ role; people must discover what comes naturally and what is most welcome and needed. In this regard, they might well be aided by a supportive and encouraging service worker.

Help people to develop and live important values. We are all familiar with values and attitudes that would benefit people with disabilities. Often we discover that we need to re-learn and re-apply these. It is an ongoing struggle to develop and live our values with a measure of integrity, yet these values are well worth the effort in terms of the way they can make life-changing differences. That is why it is important to not lose sight of values such as respect, open-mindedness, fairness and honesty. It cannot be assumed that people always understand the connection between their values and how others are eventually perceived and treated. Nevertheless, this awareness can be stimulated and



nurtured, as can be the realization that their values and resultant attitudes matter. Many service workers often provide good role models to others in regard to these, particularly when they have to struggle hard themselves to behave honourably.

Help people to stay involved with and connected to people with disabilities. Being part of a community is not just a matter of meeting people in a community, it is much more a matter of continuing to be part of a community and staying connected to its life and people. This embedding of people in community life is a process that builds one day upon another, and dividends will be paid by maintaining focus and effort. This may be made a lot easier if service workers understand and commit themselves to the continuity of relationships and community presence. When they do so, the natural facilitative process is helped along thereby ensuring that people with disabilities are more deeply an ongoing part of the life of their community.

Recognize and appreciate the contributions people make. A day hardly goes by where an ordinary person does not behave in a way that is helpful and welcome. Often, such actions would continue, strengthen and become more natural if they were noticed, appreciated and reinforced. Such recognition can help to move conduct that is tentative or impulsive into something deeper and more enduring if it is applauded and affirmed, however discreetly. Sometimes just letting people know that they are on the right track can help keep them there, particularly if it becomes clear to them that their action is welcome and needed. Service workers often play a critically supportive role in noticing small gestures by ordinary members of the community

and in encouraging them to continue and flourish.

Help people struggle for a sense of what a better community would be. If we cannot imagine better, we often fail to achieve what is possible and practical, because of our limited sense of what is possible. Even when we can see the potential of individuals we might still miss seeing what the role of an 'enabling' or 'better' community would look like. Thus it is very important for all of us to play some part in both imagining a better community and creating small examples of it. Though it may surprise some people, this often begins not with grand schemes of community change but rather in the small examples of 'better' that can be created in opportune pockets in our communities.

Consequently, these imaginative efforts at community improvement often involve everyday service workers who have a sense of mission and the resolve to make progress.

In our everyday efforts in our communities, it is important for us to remember that it is always the few that precede the many, the small that beget the large, and the obscure that humble the famous. It is important that service workers not become persuaded that their efforts do not matter, as we would all be the poorer for their absence. It is better that we see these contributions for the importance they hold, and encourage service workers in their efforts to get the relationship between communities and people with disabilities to be 'right'.

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CRUcial Times, July Issue 21

“Help people see the potential of people with disabilities. It is a common problem that most people underestimate the capacities of people with disabilities to play a larger role in community life.”



Social Capital and Trust are Good Things

Cynicism about politics and distrust of politicians are now the most striking features of Australian public life. What does this mean? And who will fix it? – by Vern Hughes

Cynicism about politics and distrust of politicians are now the most striking features of Australian public life. What does this mean? And who will fix it?

Our age is marked by a diminishing circle of trust. Corporations, trade unions, churches and politicians all find themselves on the outside of this circle. Our stocks of social capital are diminishing (that is, our capacity to trust others and to act on this trust in expectation that it will be reciprocated). The consequence is a shrinking of our social networks to people who are like us, or think like us. Disengagement, insecurity and downwards envy are the result.

The traditional politics of Left and Right cannot help us in understanding this new world. The flow of trust and reciprocity in the community cannot be adjusted by pulling levers in government or adjusting economic management devices. It cannot be legislated for. Trust and reciprocity are generated primarily in civil society, in the relationships and institutions of civil life – families, friendship groups, neighbourhoods, churches, clubs, and voluntary associations. From there they shape the effectiveness of other institutions such as the market and government.

The old politics which has given us a legacy of cynicism and insecurity is a contest between the market and the state divorced from their civil society settings. The Right wants to increase the role of the market. The Left wants to increase the role of the state. Together, Left and Right have overseen the steady expansion of both market and state for a century.

Take churches as a case study of what has happened over the last century.

Churches are voluntary associations in communities. They were once points of community gathering across ages and across

ethnicity. They were non-instrumental forms of association – that is, people did not get any direct material reward or financial benefit from their association in a church – but they gained a point of belonging, and opportunities for interaction with people who might not necessarily be their friends.

In this sense, churches were institutions in civil society. And throughout the nineteenth century and the first half of the twentieth, the churches understood themselves as part of civil society. In turn their contribution to the wider community – their social witness, in church language – was conducted through civil society institutions: charities, inner city missions, mutual benevolent societies, amateur sporting and social clubs, working men's clubs and adult education movements, women's groups, kindergartens, schools, youth clubs and co-operatives.

But as the state and market grew in the twentieth century, Christian social thought followed the trend. As the state assumed more functions and powers, it seemed proper to add the voice of the church to those arguing that the state should look after the poor, provide security and education, and act to ensure social cohesion and even 'community'.

Three things happened in this process. First, the social witness of the church was increasingly directed, not to the community or to individual persons or even to parishioners, but to the government of the day. The duty of a church member became one of barracking for the state to make a good society on behalf of us all. Christian social witness simply became a matter of lobbying.

Secondly, the relationships between people in civil society (the level of trust, belonging and co-operation between us) dropped out of the equation. The character

of persons, and their sense of duty and obligation to each other in civil society disappeared from the public agenda, and has now virtually disappeared from the social thinking of the church.

And thirdly, the church's own community (parishes, clubs, women's groups, youth groups) became sidelined in the social thinking of the church, no longer central to their social vision or how to achieve this vision. At the same time, the church agencies in welfare became service delivery instruments for governments, funded by governments, and they became the means whereby the churches made their contribution to society.

These are profound changes in one of our key institutions over the course of a century. One of the key generators of social capital in the community has almost shut down. One of the key vehicles for the society's self-reflection has almost stopped running.

Unless we rediscover civil society we cannot rediscover the source of community and the source of social capital and trust.

We need a new politics that is about making visible the relationships and institutions of civil society and remaking politics as if these matter. We need a reinvention of government so that everything a government does strengthens the bonds of association and reciprocity in civil society.

Social capital and trust are good things. A politics that takes them seriously is not 'soft politics'. It is revolutionary politics.

**presented by Sandy McCutcheon,
ABC Radio National "Perspectives" on
Wednesday 06/08/2003**

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Family Advocacy's workshops for 2004

This year we would like to reach more families whose children

- are moving into high school in the next couple of years
- are already in high school
- are leaving school in the next couple of years

One of the Kids, Part II (exact dates to be confirmed)

Mittagong, Nowra, Merimbula - 22nd – 28th March 2004

Lithgow and Forbes – 27th – 30th April 2004

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A follow up to workshops held in 2003, this day is for all parents who want to know how to enrol their child with developmental disability at their local school. The focus is on the state system, and topics include:

Relevant funding and how to apply for it;

Department of Education supports available within the school system that assist in making inclusion successful, such as Learning Support Teams and Plans, school-based and District based supports.

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Travelling through the Education Maze (exact dates to be confirmed)

A weekend, live-in event Sydney 18th – 20th June 2004

This weekend has evolved from our contact with many parents who want to further develop their skills and knowledge of how to attain and support an inclusive education for their children with developmental disability. It is for parents who believe that their sons/daughters should be welcomed, supported and taught in the regular class of their local school, irrespective of the nature and degree of disability.

While there is a nominal fee of \$30 per person, Family Advocacy covers all other costs – except for one meal – for parents around NSW to attend. We encourage both parents or partners to attend.

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NEW

Leaving school - a one day workshop about inclusive opportunities and supports for school leavers with developmental disability

North Coast (exact locations to be confirmed) End of July 2004 (exact dates to be confirmed)

Is your son or daughter leaving school in the next few years? Not happy with the very traditional programs, day activities and the like that seem to be on offer? Are you wanting some inspiration and ideas for 'what else?'

Want to know what supports and funding your son or daughter might need to achieve something that is just for them? Then this is the event for you!

To register your interest in this event (whether you live on the north coast or other parts of the state), please complete the form over the page.

NEW

One of the Kids – Moving into high school

A one day workshop for parents interested in high school inclusion

Locations to be confirmed

Mid September 2004 (exact dates to be confirmed)

Like primary school, it's good to start as early as possible when planning the move to high school. While the principles of inclusion remain the same across school years, there are also many differences in high school.

If you have a child in Year 4 onwards, are wanting to pursue an inclusive education in high school, but it seems very daunting, then this is the workshop for you!

To register your interest in this event (no matter where you live), please complete the form below.

In addition, we are planning a workshop for **Arabic speaking families of a person with disability** in Sydney in May 2004. This is likely to be about education but the topic is still to be confirmed.

We will be advertising this workshop widely in Arabic and English in the next few months. At the moment we are focussing on developing our networks, gathering relevant information, and sending out 'feelers' as far and wide as possible.

If you can assist us do this, know of someone who may be interested in the workshop or would like to register your own interest, please let us know by completing the form below.



You can send your responses by **phone - 02 9869 0866 (incl.TTY) or 1800 620 588 (freecall) fax - 02 9869 0722 e-mail – workshops@family-advocacy.com or post – PO Box 502 Epping 1710**

I would like to register my interest for (please tick the appropriate boxes)

- Leaving school – workshop about inclusive opportunities for school leavers
- One of the Kids – high school
- Workshop for Arabic speaking families
- Please contact me about the event for Arabic speaking families because I have information/contacts of assistance (we can arrange a telephone interpreting service if necessary) or you could call The Translating & Interpreting Service 131 450 and ask them to phone us (ph: 1800 726 001 Telstra Arabic Help Line)

please print

Name _____

Organisation (if relevant) _____

Address _____

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Phone (home) _____ **(work)** _____



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We're on the web!
www.family-advocacy.com

Family

Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

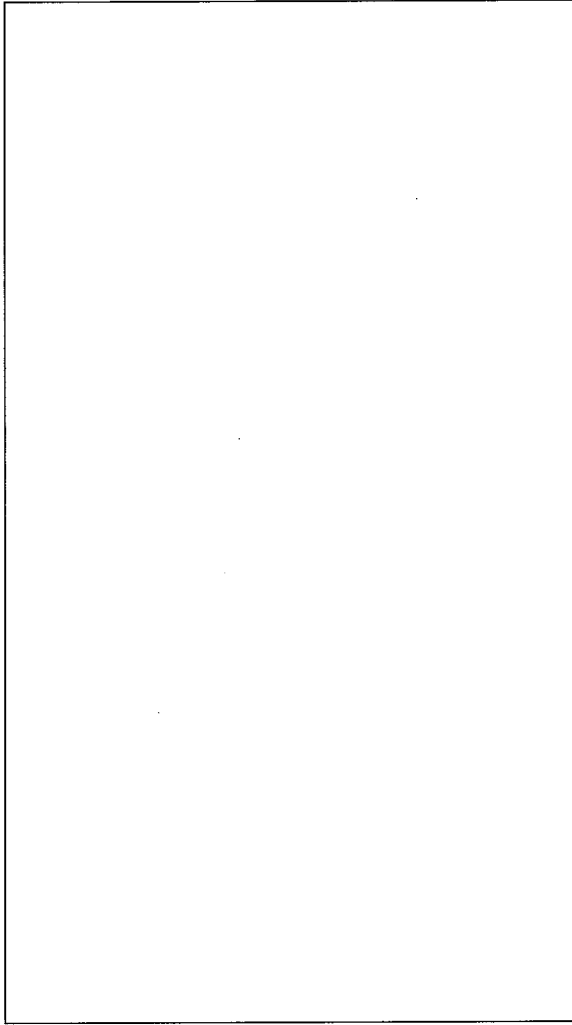
Advocacy

Standing alongside an individual who is disadvantaged – and speaking out on their behalf in a way that represents the best interests of that person.

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