

# Families for Change

## A spotlight on Advocacy

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

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ADVOCACY

At the core of the human experience rests the need to be thought of as important, to be valued as a person, to have one's fundamental needs as a human being recognised and, hopefully, met. For many of us, these things just happen. They happen as a matter of course, initially because our family provides them for us. Then eventually we take over the management of our own lives and we ensure, through our own actions, that those things we need to make our lives worthwhile are present. Generally speaking we are able to do this because we have the capacity to make well thought through decisions. We recognise what is good for us and we intuitively build on our interests and skills by working towards acquiring the things we need in life to make it meaningful and fulfilling. We can speak up for ourselves if we feel we are not being treated well, or if our needs are being ignored or trivialised. We can and do make mistakes along the way and may not always get it perfectly right, but we muddle through.

This is not the life experience of everyone. For many people with developmental disability, especially those with an intellectual disability, something additional will be required to bring about those same typical outcomes. Someone else will often need to be the voice, the instigator, the buffer, the challenger - the advocate. Social advocacy on behalf of vulnerable people is an essential element within the mix of responses needed to bring about a 'good life' for people with disability. It is a response that has been provided informally by one person for another over the years; it just was not called advocacy.

Formal, funded social advocacy is a relative newcomer onto the scene of responses for people with disability. It entered an arena dominated by human services. Advocacy and service provision are linked in that service provision should not exist without the safeguard of advocacy. They should not, however, be confused as being one and the same. To be truly effective, however,

advocacy must sit outside the human service system so as to remain independent of the inherent conflicts of interests that come with service provision. Most advocacy action is aimed at the human service system, and its many failings, and it therefore must remain unencumbered by the competing interests that will cloud and colour what should be a totally biased stand on the side of the most vulnerable person.

This concept is poorly understood by most people including governments, funding bodies, service providers and even some advocacy organisations. This has dire and far reaching consequences which have been raised over the years by a few advocacy organisations and experienced practitioners who could see where this confusion would lead. Unfortunately, these fears are being realised now as we face yet another review of the National Disability Advocacy Program. The Commonwealth Governments desire to treat advocacy as a service finds us in an environment of competitive tendering, content-free managerialism, case management and meaningless number counting.

The current review has also raised many important and equally poorly understood issues such as: who is the advocacy for; who is the best person to conduct advocacy; what skills and expertise does an advocate need to have; what forms of advocacy are needed; should agencies be supporting people with specific disabilities or should they take all comers; and what 'outcomes' should be reasonably expected of advocacy agencies? These are complex and deeply important questions which require a level of knowledge and expertise, which to some degree, has been diluted over time as the advocacy sector has struggled to maintain its integrity in the face of huge pressure to be 'all things to all people' in an environment of dwindling funding and increasing demand.

This edition of Families for Change contains five articles that bring some of the questions

and issues raised above to the fore. Shari Raymond and Jo Cross are two parents who have recognised that for their children to live good and fulfilled lives they, as parents, have had to learn about advocacy. They have incorporated advocacy strategies into their everyday dealings with the systems that impact on their children in very fundamental ways. Sandra Kalms explores what advocacy is and the different types of advocacy that are needed to ensure that people with disability have their rights upheld. John Armstrong, in his article, explains the heightened vulnerability of people with disability and the reasons why advocacy is needed, and Judith Ellis highlights the important safeguards that are needed to protect and strengthen advocacy.

For a democracy to function well all citizens should be invited to the table, and for some voices to be heard a conduit will be necessary. Independent social advocacy can be this conduit. The current National Disability Advocacy Program review provides the Commonwealth Government with an opportunity to strengthen what is currently good within the program and to identify and problem-solve around that which is not.

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# Jye the Magnificent: Making it happen

Shari Raymond

*Shari Raymond shares the story of her son Jye, who has cerebral palsy, and the importance of advocacy in ensuring Jye experiences a positive inclusive life.*

My journey as the parent of a child with a disability began very abruptly in October 2000. I stood in a doctor's consultation room with my 11 month old boy, Jye, and was told "Your son has cerebral palsy". This is how my story unfolds.

I fell pregnant with my third child, Jye, in May 1999. After a very troubled pregnancy and more weeks in hospital than at home, I gave birth to 'Jye the Magnificent' at 30 weeks in November 1999. I refer to him as 'Jye the Magnificent' as he defied the medical profession in, not only surviving, but making it to 30 weeks gestation.

For the first 11 months of Jye's life I was completely oblivious to any possibility of him having a disability. It was at one of Jye's monthly paediatric consultations, where, after examining Jye, the specialist simply stated "Jye has cerebral palsy". You could have knocked me over with a feather. Jye has what is called spastic diplegia meaning the cerebral palsy affected the muscle control of mainly the lower half of his body. Where else it effected Jye was basically a 'wait and see' situation. It was the beginning of the next phase of my family's life.

Over the next few years I experienced a variety of emotions all the while searching for a direction and needing confirmation that I was doing the best for Jye and my family. I tried to maintain a balance with the energy I directed towards Jye and the energy directed towards my other two children, Khiarn and Shardia, as well as my husband, Henry. At this point, I remained quite guarded about Jye's disability and was always hesitant in expecting that he be welcomed in to any

typical environment. I constantly apologised for the inconvenience I caused when requiring extra assistance or the rearrangement of certain furniture to accommodate Jye. I constantly felt that Jye and I had become an inconvenience. Silly me!

Looking back, I do not consider that I was a good advocate for Jye during this period. By nature I am a person that wants to make people happy and enjoy having me around even if that means much work and discomfort on my part. At this point in time I was looking out for Jye but not doing what was best for him which is what advocacy is all about.

During that time I was fortunate enough to meet up with an old acquaintance from work. As it turned out, Lyn has a little girl Hannah who is a day younger than Jye. Hannah has Down Syndrome. Lyn and I soon became firm friends. Our opinion on what we wanted for our children and our attitude towards this was very similar. So we searched for direction and support together.

Even though I had a firm opinion on what I wanted for Jye it was not until I met other people who shared my concerns, hopes and dreams that I realised exactly what I wanted and eventually how to go about achieving it. We attended workshops, seminars and information days. My first advocacy workshop shocked me for a number of reasons. It was brought to my attention how backward-thinking so many groups in our community could be. Being a non-prejudiced person by nature, I was oblivious to the large percentage of the population that were prejudiced towards those who are different. The passion of those parents

amazed me. Unfortunately, some attendees amazed me at their negativity and I realised that the positive approach was the key to good advocacy. Since then I just can not get enough information about advocacy.

I started to feel that I had a direction. We wanted Jye to have an inclusive life within the community. I knew what it was that I wanted for Jye, I could see it, now I had to work out how to ensure it happened. I was his advocate. It was important that I had a clear vision of the future I saw for Jye. Having a goal meant that I could advocate more proficiently for him.

Both Khiarn and Shardia had attended our local preschool and it seemed to be the next logical step to arrange for Jye's enrolment. Fortunately, because of my daughters' attendance and my past involvement on the committee, our family had a good, strong relationship with the staff. They had watched our story unfold and had supported me every step of the way. Fortunately, I was well supported in getting him into preschool. Nevertheless, advocacy skills were still used. I realise now that I had given them a role model of how I wanted my son to be treated. They had never had a child with cerebral palsy enrolled before and they openly looked to me for direction. In that I was grateful.

Another important step towards my advocating for an inclusive life for Jye has been Jye's attendance at the local primary school. He is now in mainstream kindergarten. Acceptance into the school was easy. There was no argument and they never hinted that Jye would be better off somewhere else. Both my girls were at the school and I

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had always referred to it as the school Jye would be attending. I thought my job was done. Nevertheless, this year hasn't been easy. Staff members are mostly welcoming of Jye's attendance. However, it is clear they do not totally understand inclusion and are unfortunately focusing more on the negatives than the positives. I do see a hard road ahead. The school has accepted Jye, but only in its physical form. The staff I have dealt with so far have a lot to learn about inclusion. My advocacy skills will be my best tool. In the meantime, and most importantly, Jye is very happy at school and is forming many friendships.

Some examples of situations that I have faced and had to 'think outside the square' involve sport at school. These situations are illustrations of events that have best tested my advocacy skills. The annual cross country race was looming and it was assumed by staff that I would take Jye home because, of course, he can not run. Why would I let that be an obstacle? I immediately thought of the brochure for the workshop *One of the Kids* where the children are all running and in amongst them is a boy in a wheelchair 'running' too. That is what Jye could do. Initially my suggestion was rejected for many reasons. They stated that an aide could not be expected to run the cross country pushing a wheelchair. I stated that I intended to run it myself. They then recommended I did not as it was very uneven ground and could be dangerous. I said that we would take that in to consideration and then my husband, Henry, gladly ran the race pushing Jye in his wheelchair. The expression of joy on Jye's face was priceless. The experience played a huge role in our struggle to show others what inclusion looks like.

Then it was the school athletics carnival. Again, it was suggested Jye have the day off assuming that it would be too difficult for Jye to sit there and be faced with a day that he could not participate in. Says who? Jye ran his age race, with me pushing him in his

wheelchair. The cheer from the crowd, the roars of encouragement from his fellow students and absolute joy evidenced by my son was all it took for everyone to understand why I didn't choose to leave Jye at home that day.

Unfortunately, it takes time to make others understand our commitment to having Jye included. During this school term, Jye's class will be involved in gymnastics as a sport over four Fridays in a row. His teacher wrongly assumed that Jye would go to another class on those occasions as "his disability would not allow him to do gymnastics". How soon they forget! So began my next quest.

Even though I made it clear that this was something Jye could be involved in, the school still requested that I personally transport him. I explained that the bus trip is always the best part of any school outing and it would provide a wonderful social opportunity for Jye. I made the necessary enquiries regarding storage of Jye's wheelchair on the bus if a disabled friendly bus was not available (as it turned out to be the case). I offered to carry Jye on and off the bus. I visited the gymnasium and discussed the situation with their staff. They were happy to accommodate Jye (with my assistance) and in fact were looking forward to the challenge of including a child with a disability in their program. Henry and I will attend each gymnastics session and be his 'legs' and his 'program co-ordinators' if

necessary. I know there will be many activities that Jye will participate in, just not achieve the same level of accomplishment as the other children. That's OK!

Without the advocacy skills that I have learnt over the past few years, I would never have been able to do any of the above with such strength, conviction, patience, determination and poise as I have. The ever-accommodating person that I used to be would have just given Jye the day off school. I would have lost a wonderful opportunity for Jye to be with his friends and for him to feel good about himself. Not to mention the tremendous joy the other children in the race and crowd experienced that day.

I have had many successes to date. Along the way I have also experienced my fair share of struggles, mistakes, criticisms and hiccups (a word I choose to use in preference to 'failures'). Each experience educates and strengthens me. The more I learn, the more power and energy I have in my quest for inclusion. It is often exhausting. Apart from the obvious physical strain, the emotional struggle of maintaining a positive attitude can be draining. It is my responsibility, however, to be the role model in behaviour around people with a disability. Jye, Khiarn and Shardia follow my lead as does Henry to a certain extent. In turn, their behaviour and understanding of his disability impacts on how their friends and family behave. So on and so on.

As my confidence grows, the less I need to consciously think about how to ensure Jye's inclusion and the advocacy skills required to achieve this. It has become almost automatic to my husband, my daughters and me. It has taken patience, control and consideration. The art of successful advocacy is a true skill and one that I am determined to continue learning. None of this would have been possible without advocacy, a tool I will use for the rest of my life.

# The Power of a Word

Jo Cross

*Jo describes her journey as advocate for her daughter, Rachael. Rachael has cerebral palsy and is currently attending a mainstream school in Morpeth, NSW.*

Before I gave birth to my daughter, Rachael, I really had no idea that a single word would be so powerful in our lives:

*Advocate- n. one who pleads the cause of another. or v. to plead in favour of a cause.*

These words from a dictionary are very simplistic and were pretty much my understanding of the word before Rachael was born. My learning curve was just about to take on the appearance of a roller coaster as I delved into the complexities and confusion that can surround this word.

My maternal instincts provided me with the motivation to advocate for my child, however those same instincts could just as easily sabotage my cause. It is very difficult to plead your cause in an assertive manner through a flood of tears, or worse a hot head with a sharp tongue. Thankfully, the latter was not a major issue for me as one of my most annoying traits, procrastination, finally came in handy for something. The main areas which I have had to use advocacy skills are in securing good health care, an inclusive education, having our home modified and negotiating adequate and appropriate respite support.

Fortunately, my work experiences have given me an understanding of a person's rights as a customer. I have enough confidence to ask lots of questions and expect to be

treated with respect. My experience with medical professionals has been very positive, however, I have had to acknowledge that they are humans like us, having varying abilities in both communication skills and their field of expertise. As a parent of a child with a developmental disability, I have taken on the responsibility of seeking the information necessary to make informed decisions and choices about who treats my child and how they should do it. I continue, therefore, asking and searching until I have a clear understanding of the situation and the choices available so that I can decide what advocacy action, if any, is most needed.

The unknown is always scary and I had no knowledge of Rachael's rights within the education system. Fortunately, our early intervention centre got my education on track. I attended seminars run by the Spastic Centre, Family Advocacy, Educare, the NSW Ombudsman and Families Supporting Families. I had no idea that I would need early intervention. I had lots to learn! What was a disability confirmation sheet? When and why did my daughter need one? What is a Griffiths assessment? Why can't our local school enrol my daughter without additional funding? Do I have a right to complain? How do I make a complaint? And so on.

School has provided me with many challenges where I have had to use all my advocacy skills to ensure that Rachael is being seen as a student with strengths and skills rather than a problem to be dealt with. I have felt my knowledge and confidence has grown over the years, which has also enhanced my advocacy skills.

In the early days I had to deal with intimidation tactics and hurtful comments which may have been motivated by fear of the unknown and ignorance. Initially some of these situations affected my judgement and I made decisions that I really was not happy with, but I felt like I was backed into a corner. These decisions did cause me grief for a time. The skills, however, I acquired through being an advocate for Rachael taught me to put these negative situations into perspective by understanding that I probably was not the only one feeling backed into the corner.

Whilst advocating for Rachael I have been encouraged to prepare for every scenario to enable me to better deliver a convincing argument on her behalf. I try to predict questions that might be asked during a meeting and I put my answers or explanations in writing. For example, I was asked why I disagreed with various forms of IQ assessment. I gave my opinion and suggested a scenario. If someone came into our school and wrote a report on each child

highlighting their shortcomings and offering no practical solutions, there would be uproar as parents defend their children. So why should I react any differently! This is a difficult statement to argue.

I now avoid ‘corners’ by continuing my research and ensuring I have a good understanding of Rachael’s rights. I then look for options that address Rachael’s needs without selling out on our goals. Advocacy does take a lot of energy especially when it involves emotions, but with good planning I can have the confidence to say no when I believe Rachael’s best interests are not being served and feel knowledgeable enough to know what to go into battle about and what to let go.

My journey learning about advocacy continues. My daughter’s classmates had a thing or two to teach me. On one occasion they came to me very distressed with details highlighting a situation where my daughter was clearly being discriminated against in front

of her peers. Although this was a negative situation it had a lovely positive side. The school as a whole was guiding its own young advocates to recognise and report wrong doings. Unfortunately, I

***“My daughter has empowered me to be a much stronger and capable person”***

then had to deal with the negative side – a formal written complaint to the Department, meetings to address the complaint and negotiated strategies to ensure the incident does not happen again. I took a support person with me to the meeting which ended with a positive outcome. I feel this was partly due to the preparation we had done prior to the meeting and the fact that I kept focused on the

issues highlighted in the written complaint. I took copies of the complaint so that every one could follow and keep on task. This also helped me keep focused and to avoiding a deluge of emotions or worse a personal attack.

All of the actions I took stemmed from my understanding of advocacy and the important role these strategies play in ensuring Rachael’s rights as a member of the community are being upheld.

My daughter has empowered me to be a much stronger and capable person. I was a quiet and reserved person who would walk on eggshells to avoid confrontation. Now I stand my ground striving to create a positive future for my family. The simple meaning of the word ‘advocate’ has had a great impact on our lives. Advocacy has encouraged me to brush up on my communication skills and learn the deeper meanings for other words like ‘assertiveness’, ‘diplomacy’, ‘empathy’, ‘respect’, ‘forgiveness’ and ‘understanding’.

# Diversity in Action

Sandra Kalms

*Sandra Kalms has 15 years involvement in advocacy for people with disabilities and their families, most recently as Coordinator of Queensland Parents for People with a Disability. She is currently at the Community Resource Unit where projects which strengthen the family movement, influence the ways that people with disabilities are supported, and provide avenues for the sharing of information.*

What is advocacy? Is the need for advocacy any less in 2006? Are certain forms of advocacy more important than others? Is advocacy considered to be an essential component in ensuring that people with disabilities have good lives? What is the difference between advocacy and support? Does advocacy actually achieve anything?

These questions are being raised in the context of the current Commonwealth Government’s review of the National Disability Advocacy Program and have prompted advocates and advocacy organisations across Australia to revisit the nature and importance of advocacy.

It is appropriate that the National Disability Advocacy Program funds only those things which are advocacy and that the small amount of funds are distributed in a way which provides a range of advocacy responses to meet the diversity of advocacy needed.

While, however, it is a relevant and important role for Government to ensure that public funds are spent wisely, this cannot be at the expense of losing independence. Advocacy organisations will only be effective if they are able to maintain a minimal conflict of interest by being on the side of people with disabilities and remaining loyal and accountable to them over the long term.

It will be easy in the current context for advocacy groups to be pitted against each other, scrambling for the small amounts of funds on offer. It will also be tempting to compromise the principles and independence of advocacy in order to receive funds. There is simply not enough advocacy to go around and the real need is for more advocacy not a redistribution of advocacy dollars. It is therefore vital to remember that the following forms of advocacy are equally important and have both strengths and limitations.

#### **Unpaid Individual Advocacy**

The most common form of advocacy is when family members or friends act to promote, protect and defend the well being of the person they care about. This form of advocacy happens almost unnoticed as people go about their lives doing what they need to do because it needs to be done. The strength of unpaid advocacy is that the advocate knows the person intimately and has a strong sense of the person's history and identity. A challenge for unpaid advocates can be the cost of doing advocacy in an isolated way with few resources.

#### **Self Advocacy**

In this form of advocacy, people with disabilities are assisted to represent their own interests or the interests of people with disabilities generally. The difficulty for self advocacy is that sometimes those who are undertaking the advocacy and speaking up for themselves are exposed to even further abuse, discrimination and ridicule as a result. The strength of self advocacy is the natural authority of people with disabilities in talking about injustice in their lives.

#### **Citizen Advocacy**

Citizen advocates are unpaid members of the community who, with support

from a Citizen Advocacy agency, represent the interests of a person with a disability in an advocacy role, some of which may last for life. The strength of this form of advocacy lies in its freely given nature, minimal conflict of interest and the power of ordinary citizens speaking up and standing beside individuals with disability. A limitation can be a tendency to over emphasise the relationship side so that it becomes a 'friendship program' only.

#### **Paid Individual Advocacy**

Another form of individual advocacy is community based organisations that pay staff to advocate for individuals. Paid advocates have skills and experience in the elements of advocacy – speaking, acting and writing. The strength of paid individual advocacy is it often represents the interests of people who do not have the support of family and friends. A limitation of paid individual advocacy is the capacity of paid advocates to be consistently there for a person over the long term.

#### **Paid Systems Advocacy**

This form of advocacy is primarily concerned with influencing and changing the system (legislation, policy

and practices) in ways that will benefit people with disabilities as a group within society. Paid systems advocates are concerned with patterns of problems, difficulties and shortcomings with systems and usually do not do individual advocacy. The strength of paid systems advocacy is its focus on the broader issues and its capacity to influence positive change for many people. A challenge for paid systems advocacy is remaining close to the people it advocates for and remaining independent from the systems it advocates against.

#### **Collective Systems Advocacy**

Collective systems advocacy is conducted by the voluntary efforts of a group of members who give their time and expertise in a number of roles and capacities. Collective systems advocacy provides a vital link between the efforts of unpaid advocates and the systems for whom they come in contact. Collective advocates are commonly family members/parents and are generally supported to do advocacy by paid staff. The strength of this form of advocacy is that it remains close to people at the grass roots and provides a mechanism where people can join together for collective action. The limitations of collective systems advocacy are the potential conflicts of interests around what is advocated against and for.

#### **Advocacy Development**

Advocacy development is the actions and practices that enlist the energy and commitment of individuals and groups in our community to take on advocacy. Advocacy development strengthens advocacy efforts by inspiring, encouraging and skilling potential or existing advocates. Often advocacy development efforts are conducted by family or parent based collective advocacy groups.

The diversity of advocacy responses enable a wide range of potential advocates for vulnerable people. Just as there is not one response to the housing needs of people there should not be one response offered as a means of protecting and promoting the welfare and rights of people with disabilities. If we are sincere in our efforts to ensure

***“The most common form a advocacy is when family members or friends act to promote, protect and defend the well being of the person they care about.”***

that people are safe and have decent lives then we must support people with disabilities, family members, paid staff and citizens to take on individual advocacy roles. But that is not enough. We also need to ensure that the issues that people have in common with the structures, practices and attitudes of society and systems are advocated for at the systems level.

In 1977, Dr Wolf Wolfensberger named one of his first publications on

advocacy *A Balanced Multi-Component Advocacy/Protection Schema*. He was very clear that for a national or state advocacy response to be effective it needed to have multiple components. In the coming months and years let us remember that "together we are better" and that a diverse advocacy response, in its own right, may be the most important element in ensuring that the interests and well being of people with disabilities are promoted, protected and defended in Australia.

***“The diversity of advocacy responses enable a wide range of potential advocates for vulnerable people.”***

# CRU 07 CONFERENCE

26, 27, 28 February, 2007  
Brisbane Convention and Exhibition Centre

**Myth Busting and Momentum Building**  
**A Community Conference about Truths in the Lives of People with a Disability**

## About the conference

This conference is a search for those truths that are most likely to give inspiration and hope. It will encourage us all to continue to seek better ideas and better ways to create circumstances that foster rich and meaningful lives for people with a disability.

'Bigger services are better.' 'Small services are better.' 'Blue cards are the answer.' 'Group homes, villages and cluster housing are the answer.' 'Community has the answers.' 'Government has the answers.' 'Money is the answer.' Many of us feel confused by the many mixed messages that are promoted as if they were total and final truths. It concerns many people across Australia that there are some voices that are heard, at the expense of others.

This is the sixth conference to be hosted and organised by Community Resource Unit. It continues CRU's tradition of inviting people with a disability, family members, service workers and academics to share both the stage and the audience.

We hope that you will join with us and join with others to continue to celebrate the achievements and the possibilities in the lives of people with a disability and their families, to explore the current challenges and to further the community living movement.

Visit [www.cru.org.au](http://www.cru.org.au) for further conference information, including:

- Program updates
- Maps
- Accommodation options
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# Safeguarding Social Advocacy for People with Disability

Judith Ellis

*Judith Ellis has been active in the advocacy movement since the late 1970's. She was the founding Director of the Commonwealth Office of Disability and a former policy adviser at NSW State Ministerial level. She has served on both State and Commonwealth Advisory Councils. Judith is the parent of a man whose disability means that he has very high support needs.*

Twenty years ago formal recognition of social advocacy for people with disability at the national level happened when it became part of the original *Disability Services Act 1986* (Cth). In its comparatively short life social advocacy has significantly improved the lives of many individuals with disability and achieved very significant outcomes in law reform, policy, and access across an array of systems; education, housing, community support, employment, accommodation support, and transport, to name a few. Furthermore, it has made significant inroads into improving community attitudes. Overall, social advocacy has fundamentally altered the social, political, and economic environment for Australians with disability at both the personal and systemic level. It is therefore a time for celebration, a time for reflection of its achievements and a time to consider the future and the continuing struggle.

Recognition of advocacy in 1986 was not solely a Commonwealth Government initiative. Rather it responded to people with disability and parents who were no longer prepared to put up with others making decisions about their lives, who had previously had no voice, or whose voice was largely ignored. As with any movement, it grew and developed from a grass roots base. This is one of its strengths because building upwards from the community almost always brings about diversity. In the case of advocacy, a broad 'church' of forms developed. Some were set up to be small and local, or regional, speaking out for individuals on a paid or voluntary basis. Other forms emerged including those which were statewide and focused on the government and non-government systems which affect people with disabilities. In addition, some approaches recognised the need for legal advocacy. Others were educative

and concentrated on developing leadership as well as responding to cultural diversity and the needs of aboriginal people with disability. It is this broad and diverse approach which has contributed to positive change over the years.

Far from 2006 being an occasion to mark this important anniversary, much energy is instead being used to ensure that advocacy remains an effective voice.

From the early 1990's, government and bureaucratic reviews of funded social advocacy for people with disability seemed to become part of the landscape of what was then a fledging movement. To some it might appear these reviews have been more numerous than those of the hugely bigger direct service system. One example is close to home. The NSW State Government has been involved in a 'reform plan' for several years and still has no clear direction as to the future of independent advocacy and information in NSW (which receives only a tiny percentage of funding compared to direct service provision). It is deeply concerning that the State Government's \$1.3 billion dollar 10-year plan does not provide any additional funding for advocacy. In the late 1990's, a national review saw the virtual demise of citizen advocacy, its role of matching unpaid ordinary citizens to advocate for people with intellectual disability subsumed by paid advocates.

Towards the end of 2005, yet another national review was announced. Its implications are only now becoming apparent. At this stage, the suggestions do not augur well as a means of building on the achievements, experience and commitment of the formal advocacy sector.

It is an interesting fact that there appears to be a relentless push by the State and

Commonwealth Governments to review a system which is so infinitesimal compared to the money invested in direct human services. Questioning this, however, often invokes a flurry of accusations such as advocacy agencies do not want to be held accountable, are not willing to change, or are self-serving and self-interested. The evidence says different.

Most people accept that the system of advocacy needs improvement and strengthening. In the short twenty years of its life, it would be hard to find an advocacy agency that does not think it can and should do better. All agencies have funding contracts, make regular reports to their funding bodies against their agreed yearly plans, collect data, write about what they do in annual reports, and account for the money they receive. What most have said is that accountability is crucial. They also say that governments need to bring in accountability measures and mechanisms which reflect the true nature of advocacy. Community-based advocacy practitioners have taken time to contribute ideas on accountability mechanisms but most suggestions have been ignored, and agencies still have to collect largely irrelevant data which has not assisted advocacy become more effective.

So why do reviews appear to avoid recognising the strengths of this important contribution to the lives of people with disability and why do they nearly always come up with recommendations that, to most experienced advocacy practitioners, will only serve to weaken it? One can be forgiven for thinking that social advocacy is regarded as simply an unwelcome irritant to more powerful individuals and entities, including governments, service providers, the wider community and even sometimes parents of children and adults with disability. If, as many believe, this is the real issue, then it will always be under threat.



At this particular time, when so much energy is being used defending advocacy, considering what it would take to create a stronger system for the future feels out of place and even profligate. History, however, tells us that a renewed approach to safeguards is needed. Complex issues are not solved by simple solutions and it follows, therefore, that there needs to be a multiplicity of protections for advocacy so that it is better able to withstand the continual pressures to weaken and rationalise it.

Independent advocacy will always be situated in a culture of divided views. After all, it swims against the tide of attitudes to, and opinions about, the place of people with disability in the community. Arriving at a shared description of advocacy and developing guiding principles is a very important safeguard. It is vital to arrive at a point where there is agreement about the difference between social advocacy and other things that are good, but not advocacy. Independent social advocacy is not case work or case management. It is not a 'value neutral' information service. It is not service provision or lobbying by industry bodies. It is unashamedly biased, speaking out for individuals or groups of people who are the least powerful. It stands firmly on the side of the person, or people, with disability. In addition it needs to be able to take up issues on behalf of people irrespective of whether they can personally contact advocacy agencies. This group of people may be children, or individuals who have lived in institutions for most of their life, or those whose disability means that they do not understand that they are subject to abuse, neglect or exploitation and that their lives could be very different. In this context, advocacy's role is to take on the best interests of people with disability as full and participating members of the community.

The process of finding some clarity between what is and is not social advocacy would act as a way of building and strengthening relationships within the advocacy movement. When resources are tight, it also often happens that organisations vie with each other, so remaining in effective contact with others in the advocacy movement is vital. This

would result in a more united voice, more capable of influencing government to play its part and establish, through a consultative process, accountability and reporting mechanisms which are specifically relevant to social advocacy and which will help it develop.

One of the common arguments heard from governments is that they have to listen to too many voices. This invariably results in a drive to rationalise and narrow the diverse forms of advocacy which are

*“The diversity of advocacy responses enable a wide range of potential advocates for vulnerable people.”*

such a source of strength. While it was citizen advocacy that was in the firing line some years ago, now it is systems advocacy. It might suit governments to have only one systems agency in each state, but it would be disastrous for people with disability. Rather the argument is more about what creates a healthy tension and a robust environment in which the needs and rights of people with disability can be debated and be responded to positively.

No one systemic advocacy agency can respond to the complexity of issues which arise from very different social situations. Some groups which are broadly consumer based might be spending their energies on the barriers to the use of public transport or on accessible housing. Others which act to promote the interests of children and adults with significant intellectual and multiple disabilities, will be likely to be concentrating on different priorities. They will be engaged in dealing with exclusionary practices of the education departments, or raising ongoing neglect, abuse and exploitation of adults in

supported accommodation and residential facilities. Some will continue to press for people to move out of institutions so as to enjoy the opportunity to lead a life as part of the broader community.

In any event, at a practical level, no one systemic advocacy agency will have the resources or the expertise to deal with everything. If this were to be the case, it is highly probable that the most vulnerable individuals and groups of people will, once again, miss out.

It is true that the main focus of advocacy are the societal barriers that a person or group encounter in having their rights and interests addressed and recognised. The view that all advocacy agencies should respond, however, to people with a wide range of differing disabilities is simplistic. Once again, this notion ignores complexity. Principally it denies that, for some people, the nature of their disability results in a vastly more complex and difficult set of barriers to overcome. The advocacy needed to address this lifelong denial of rights is long-term and unremitting requiring different experience, different resources, different approaches and different strategies.

While much has improved over the past twenty years, and there is much to celebrate, there are still massive injustices and barriers to people with disability participating in and enjoying the good life and contributing to the Australian way of life. Growth of human services at both Commonwealth and State levels is not a signal that less advocacy is needed. The opposite is actually the case. The 'little' people get lost as structures and systems get bigger and more complex. They will need more of a voice, not less.

It is up to the governments of the day, as it was twenty years ago, to acknowledge that they will always have to listen and deal with differing points of view. It is a role of government to listen to the disparate voices, to be open to the criticism that advocates are bound to make about the system, to sift through a variety of suggested ways ahead and then to make decisions based on the values and principles which are enshrined in the legislation of this country.

# A Rationale for Advocacy

John Armstrong

*John Armstrong conducts workshops in Social Role Valorisation and performs consultancies, including working with families and conducting service provider evaluations across Australia and New Zealand. He also conducts Board training and development for Citizen Advocacy programs. He is the inaugural President of the Citizen Advocacy Trust of Australia, an organisation established to raise funds to support the continuation and development of Citizen Advocacy in this country.*

Advocacy is needed because a person or class<sup>1</sup> of people exist in a state of peril.

All of us from time to time require assistance with something that is out of the ordinary; a threatened job, a contract gone wrong, a neighbourhood dispute. We might need someone with specific expertise to represent our interests so as not to be unjustly or unfairly disadvantaged. Sometimes they are someone from our network, or someone our network places us in touch with. On other occasions we might have to pay for such representation. Usually we hope that those occasions are rare if necessary at all.

Some people, including people with disabilities, experience ongoing potential for disadvantage. This is mostly due to the low status accorded them virtually automatically and reflexively by other people and society in general. This form of disadvantage has sweeping repercussions, including the outrageous prospect of being regarded as less than fully human as the normal expectation of society. Such a perspective opens the person and indeed the whole class of people to every manner of neglect, disadvantage and discrimination. The mere 'membership' to such a devalued group provides a societally sanctioned prejudice that is potentially played out at both the personal and societal level, including formal structures like education, welfare, health, the courts and human services.

There are two very important aspects to this set of circumstances:

1. An increased likelihood that people will experience frequent and relentless hardship and disadvantage including damaging experiences such as rejection, low expectations, attachment of negative symbols and images and loss of control.
2. The impact of these experiences is more pervasive and devastating because there is little to mitigate the effect.

For valued people, legal standing, education, financial credentials, valued roles and reputation, friends and networks all stand to significantly dampen the effects of bad experiences. Once devalued however, these usual protections are significantly missing or neutralised even if and when they do exist.

Thus people caught in this situation exist in a state of heightened vulnerability. It is this unremitting state that makes effective advocacy such a necessary and prolonged activity. Effective advocacy is reliant on the clear realisation that the above risks indeed exist.

Such a disadvantaged state demands strong and effective, therefore potent, advocacy.

The potency of the advocacy is reliant on the independence and legitimacy of the advocate in preventing, reducing and compensating for the (potential) disadvantage the person faces.

While people will often face heightened risks unique to them such as certain health, appearance and abuse risks, many

threats will also include those common to all members of that class - such as reputation risks. Thus some advocacy efforts will be directed not only towards an individual but could also serve the interests of other parties<sup>2</sup> within the class, and sometimes all people who are devalued across classes.

***“Such a disadvantaged state demands strong and effective, therefore potent, advocacy”.***

Thus advocacy is the speaking, acting and writing towards the real interests of a socially and sometimes physically weakened party, on behalf of *their* interests and no one else's. To do this effectively, the advocate must be in as strong a position as possible, including their legitimacy, social standing and independence so that those interests can be represented without a diluting conflict of interest.

If we fail to recognise the real and potential perils that befall devalued people, we will probably fail to rally the needed advocacy on their behalf, with devastating results – on them.

<sup>1</sup> Class here means a collective of people who are distinguished by some attribute in the minds of other people. For example, people who are intellectually disabled, people with Down Syndrome, or with autism, or are refugees, might all be seen as a class by others in society – each carrying its own set of stereotyped expectations that is then applied to all members of that class.

<sup>2</sup> Parties here may be other individuals, a group, or indeed all members of the class.

# Resources from the Inclusion Collection

*Below is a selection of resources about the topic of this issue, advocacy. You can order articles, books, videos and kits from the Inclusion Collection online on [www.family-advocacy.com](http://www.family-advocacy.com) or by phone on (02) 9869 0866 or 1800 620 588 (for non-metropolitan callers).*

## **Remembering where our loyalties lie**

**File: 10506**

This brief article summarises where an advocate must place their loyalty and lists some people or groups who may be involved with the person they are an advocate for, but for whom they do not owe loyalty.

## **Parents as Advocates**

**File: 10491**

Kevin Stone writes a submission and a set of recommendations concerning the advocacy role that parents need to take (in partnership with consumer based advocacy movements) in order to ensure effective service delivery and services that meet individual needs as opposed to the needs of staff, the needs of agencies or other professionals. Stone also documents the historical role that parents have played in fighting for services other than institutions, but how this led to their co-option into the services - on management committees or directly providing services. Stone argues that parents cannot be effective advocates when they are also in this role of 'provider'. He documents ways in which parents can still be involved in the services provided to their sons and daughters, but how this involvement can be meaningful and truly be in the best interests of their children.

## **Parent Advocacy**

**File: 10196**

This brief information sheet provides a definition of parent advocacy and what it is not, and some of the things a parent advocacy group can do. Addresses of two Queensland and New South Wales advocacy groups are given.

## **Mobilise**

**File: 10175**

This article encourages parents of children with disabilities to become more assertive. It shows how effective assertive statements are when compared to aggressive or non-assertive statements,

and how assertive behaviour gives one strength "to take on the world". It discusses body language and the value of working in partnership with your allies, giving ideas on how to identify allies. This article references United States regulatory bodies. Please contact Family Advocacy for the relevant Australian equivalents.

## **Integrity and Advocacy**

**File: 11011**

Michael Kendrick asserts that the question of integrity is highly pertinent to advocacy, whether the advocacy is undertaken by individuals or by groups or organisations. This paper considers 'integrity' in relationship to advocacy undertakings and suggests that a compelling standard of integrity would require that the scrutiny of an advocate be just as unrelenting as the advocate is of others. The paper sets out a selection of dimensions of integrity which the paper urges the advocates to examine. In doing so, it focuses on key attributes of effective advocates.

## **From rage to reform: What parents say about advocacy**

**File: 10547**

This is an excellent article on parent advocacy and why it is such a powerful role/task. One of the main sources of this power is anger and using anger as a positive force for change. The author also discusses the importance of support groups, what is involved in the move from 'personal' to 'public' advocacy (although it does not discuss the risks involved in this move) and the importance of family involvement.

## **Advocacy**

**File: 10057**

A checklist of nine tried and true strategies for parent advocates who wish to affect changes in the system for their son or daughter. While the article comes from a book relating to parents and

schools, it is relevant for broader advocacy efforts.

## **BOOKS**

### **Tool Kit for Advocacy: a human rights framework for persons with disabilities**

**File: 3204**

This is an excellent tool kit for families, people with disabilities and all those wanting to create change for people with disabilities. The tool kit came out of a workshop, Developing Advocacy for Persons with Disabilities, which was held in Kingston, Jamaica in 1995. The targets and strategies for change in the tool kit form a dynamic community action plan, placing the ability to create change squarely in the hands of the people with disabilities and others in their lives.

### **Daring to Dream: Stories of parent advocacy in Queensland**

**Author: Jennifer Barrkman**

**File: 3280**

'Daring to Dream' is a collection of biographical stories around the theme of advocacy for people with disabilities. It tells a history of several families involvement with the organisation 'Queensland Parents for People with Disabilities' and how advocacy became the key to achieving their dreams for their family member. The book explores ways of dealing with the inflexibility's within the system and gives examples of the different approaches that have been taken by families.

## **VIDEOS**

### **What is Self Advocacy?**

**File: 104**

People with intellectual disabilities talk about self advocacy. Areas covered are: speaking up for yourself; learning to do things for yourself; having rights and responsibilities; making friends; and helping each other to change things.



If undeliverable, return to:  
The Institute for Family Advocacy  
and Leadership Development  
PO Box 502  
Epping NSW 1710

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Freecall: 1800 620 588  
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familyadvocacy@family-advocacy.com

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[www.family-advocacy.com](http://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.

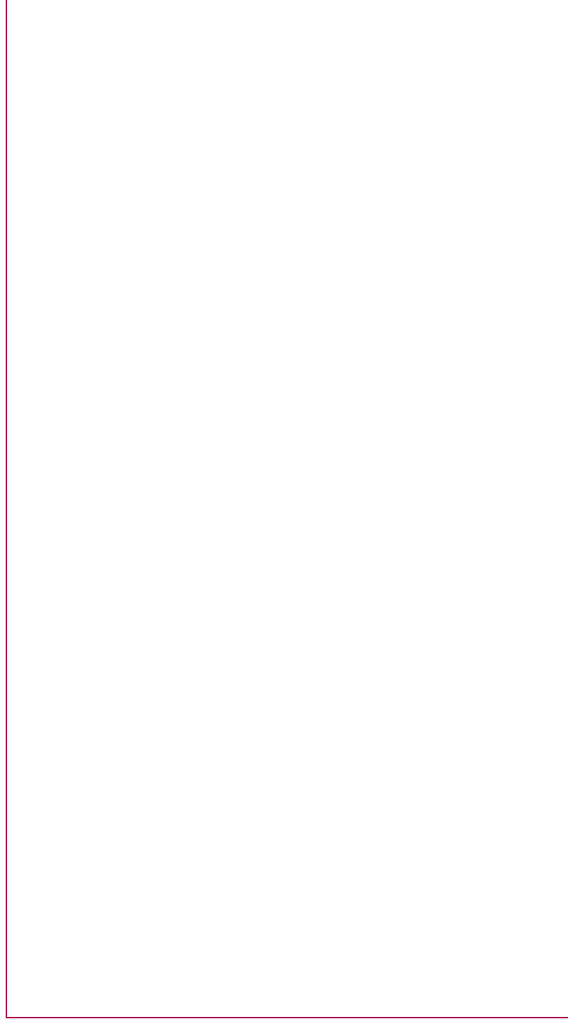
## Advocacy

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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A D V O C A C Y

Institute for Family Advocacy & Leadership Development Assoc. Inc.

A New South Wales association concerned with the rights and interests of people who have a developmental disability

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November 2006

As you know, Family Advocacy distributes the journal *Families for Change* free of charge to families who have a member with a developmental disability. We believe it is important for all families to receive this publication as we consider it an essential piece of our work. Over time, however, the costs of publishing and distributing the journal have risen substantially. Family Advocacy has decided not to charge a subscription fee for families, but we would appreciate any contribution towards the journal's production costs families could make.

If you wish to make a voluntary contribution to the journal, please fill in the form below and send it back with your contribution. All donations over \$2.00 are tax deductible and will receive an official Family Advocacy receipt.

Please be assured that you will continue to receive the journal whether or not you make a voluntary contribution.

Warm regards,

Catherine Hogan  
Director

Please return to: **Family Advocacy, PO Box 502, Epping 1710**

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