

# Families for Change

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

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family

A D V O C A C Y

## Social Advocacy in a complex and changing world

Social advocacy on behalf of people who have a disability has been around for a long time. Families, particularly, have been speaking out for many, many years. They were responsible for gaining access to a public education for their sons and daughters at the time when society deemed children with disability to be ineducable. In addition, it was families who demanded that their sons and daughters should not have to be placed in institutional care when that was all the system offered.

Advocacy agencies are a more recent occurrence and since Citizen Advocacy first started in the United States nearly 40 years ago, several different forms of formally organised advocacy have developed.

Increased reliance by Government and service providers on a technological and managerial approach, the transformation of community-based service providers into multi-million dollar industries, a focus on competitive tendering processes to provide support to individuals with disability, combine to mean that there is a much higher potential for people with developmental disability to be denied their rights as human beings, to not be afforded the support to participate in the life of the community as a person who has gifts and contributions to make, and to face potential and real harm, neglect and abuse.

As the complexity of the system has increased, so too social advocacy has had to develop a variety of ways to ensure that the voice of people with disability is heard and acted upon.

Some advocacy agencies focus on what needs to happen at a systemic level to bring about a positive, fully inclusive future for people with disability and what this might look like. They speak out for new and existing funds to be allocated in ways that will make a real difference. Family Advocacy's current campaign - directed at the Government and non-Government system - for a Supported Living Fund and for more individualised funding to be made available, is an example of this form of advocacy. More flexible and individualised funding, properly implemented, will give individuals with disability and/or their families real control over their own lives rather than having to fit into what powerful service providers and Governments have decided for them - usually typified by a throwback to the past, segregated, and non-individualised.

Other advocacy is directed at reminding Governments of promises that have never materialised for largely political reasons - witness the ongoing advocacy needed to get the State Government to close institutions in NSW. Many advocates and advocacy agencies will remember that this promise was first made about 30 years ago. It goes without saying that strong and consistent advocacy is needed in the long-term!

At the individual level, advocacy is undertaken to prevent people who are very vulnerable being harmed and stopping exploitation and neglect.

Parents will undertake advocacy in order to promote the dignity and rights of their son or daughter and to ensure that they are able to achieve roles which are valued and to participate and belong as full members of our society with the support they require.

In this Journal, a number of individuals who have spent years working in social advocacy describe the various ways in which the interests and rights of individuals with disability are promoted and defended.

The different types of advocacy complement and inform each other. If the system changes for the better, then this will have a positive effect on individuals with disability. At the same time, the issues and barriers which face individuals inform the advocacy needed to change the system.

All the articles speak to the importance of a commitment to guiding principles such as independence from Government and the service system, reducing or eliminating conflicts of interest, strong and life affirming values and beliefs, and the need to ensure that advocacy efforts can continue in the long-term.



As the festive season approaches, all of us at Family Advocacy join in thanking you for your action, support, stories of change and membership and in wishing you peace, hope and successful advocacy efforts in 2011.

### Inside this issue:

|  |          |
|--|----------|
| <b>Editorial:</b>  | <b>1</b> |
| <b>Advocacy - The Foundation of a Positive Future</b>                        | <b>2</b> |
| <b>Citizen Advocacy: Meaningful Relationships</b>                            | <b>3</b> |
| <b>Individual Paid Advocacy</b>  | <b>4</b> |
| <b>Systemic Advocacy - Creating Positive Change Within the 'Big Picture'</b> | <b>6</b> |

# Advocacy - The Foundation of a Positive Future

Matthew Kelly

*Matthew Kelly is a family man and works as a book publisher.*

After discovering that our daughter, Bridget, had a disability, we quickly came to the realisation that she has the same rights as everyone else to reach her full potential. As far as we are concerned, the goal for our daughter is that she be able to live independently and work in a sustaining and rewarding job. Our advocacy on her behalf is directed towards her achieving such goals.

None of Bridget's current achievements came about easily. We found that - as we had to take on the role of advocate to achieve these ordinary aspirations - we firstly needed a philosophy and framework that would help us work towards building a positive future for her. To that end, we made connections with individuals and organisations whom we felt would help us on the journey we were taking.

Bridget has recently started Year 7 in a mainstream high school - after attending the local mainstream primary school. The benchmark throughout was the wider benefits of being part of the school community - being with regular children and, as far as possible, taking part in what they were doing. Irrespective of what she actually achieved, she certainly benefited from being in that environment with the expectation that she would be taking part to the best of her ability.

As Bridget is now in high school, we consider it important that she catch the school bus just like everyone else. To us, seemingly small things such as being aware and capable of doing such things are vital parts of her school experience. Catching the bus is symbolic; it signifies that she is learning how to be independent. It is a practical skill for now and into the future.

Bridget is a proficient swimmer. She has achieved the State finals of the Public School Swimming Association. This achievement cemented her reputation amongst her sisters and friends at school as a swimming champion! Be it at the pool, or at the beach, Bridget is able to hold her own.

A great deal of behind-the-scenes work has been necessary to make these things possible and to keep them happening. Getting a decision on a principle or policy is not the hard part. The hard part is getting something to happen and that's where advocacy comes into play.

***Being an advocate means standing in the person's shoes - we are not advocating for ourselves but for our daughter.***

It has meant getting to know teachers and school authorities and keeping in touch so that we know what is coming up and are ready with a strategy to help deal with a situation. We have found that it is important not to be adversarial or combative - you gain nothing by getting the name of 'a difficult family'. It does mean developing a thickish skin so that we are not ground down by others being forgetful or thoughtless in their words and deeds.

The thing we have learned about all kinds of advocacy for - and by - those living with a disability, is that it is going to be needed in the long-term. In every situation, it seems that the person with a disability is treated as the exception rather than the rule and society seems to find *not* treating them as a person with dignity and rights is the easiest and most pragmatic thing to do - it's either a case of being totally ignored or simply forgotten.

This is not to imply that there is any intentional hostility on the part of others, or even the system. It is simply that the system forces you, or the person living with disability, to confront the reality

that you have to be one step ahead and have a strong and positive vision of the future.

Being an advocate means standing in the person's shoes - we are not advocating for ourselves but for our daughter. The issues we take up are not necessarily about getting more services; they are about ensuring access to a wide range of everyday, mainstream roles, as these are what will build a future for Bridget where she will have opportunities to contribute to the wider community.

Mostly, a parent advocate is the only person with a holistic approach - the only one who knows their family member well, who will be around in the long term, who sees the whole picture. Many others are kindly and well-intentioned but they are only dealing with part of the whole situation with one segment at a time.

An advocate has to be there in the long term, planning, persuading, supporting. It takes resilience on the part of an individual or family to be an advocate. The path towards any one goal or achievement is marked with innumerable points where support and advocacy are needed to remind/push/influence/change those involved. Given work commitments, worry and the day-to-day demands of everyday life, it can be easy to lose perspective and judgment, so being in contact with others who share common values is very important.

It all comes down to being an effective advocate - someone who knows the person very well, someone who can help plan their life, both in the short and long-term. It means recognising that, while you can't force people to be compassionate and caring, you can be uncompromising by standing up for someone living with a disability. A parent taking on the role of advocate has to be uncompromising, skilled and an effective problem-solver. It means having a combination of vision and a strategic plan and a realisation that everything has to reflect the best interests of the person with disability.

# Citizen Advocacy: Meaningful Relationships

**Bob Lee**

*Bob Lee has been involved in providing services for people with disability since 1978 and since 1984 has been actively involved in advocacy efforts aimed at protecting and defending the rights of people with disability.*

*Bob has completed a Bachelor of Arts degree at the University of Queensland and a Masters degree in Human Services at Griffith University.*

*In 1996, Bob was employed as the co-ordinator of the Sunshine Coast Citizen Advocacy Program and continues to work in that role. A primary function of the citizen advocacy coordinator's role is to recruit and provide training and support to members of the community who provide independent unpaid advocacy to people with intellectual disability.*

Citizen advocacy is just what it says - advocacy for people with disability undertaken by competent, responsible citizens of good standing in a community. Essentially, citizen advocacy recognises the impressive capacity of citizens to advise, guide, influence and protect each other and harnesses that capacity to benefit those members of the community who most often miss out...vulnerable and isolated people with disability.

Most of us would be familiar with the phrase 'friends in high places'! We know that it is not really about friendship. It is about being connected to others who are willing and able to offer their influence, knowledge, skills and experience to assist you in your life. What it means is that those who are 'well connected' are also likely to be successful and secure and unlikely to be isolated and vulnerable. Citizen advocacy makes these good connections for people with disability by seeking out and inviting members of the community to become citizen advocates. Advocates are carefully matched with the person who needs advocacy, by matching the person's needs, with the citizen advocate's skills and experience.

Citizen advocates receive ongoing training and support from the citizen advocacy program. Advocate associates provide a comprehensive range of resources and professional and technical advice and support which serves to make the 'non-professional' advocate highly effective. Importantly, citizen advocates do not need to be expert in all issues relevant to people

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with disability. Just like parents or family members conducting 'family advocacy', they are involved with one person and therefore become knowledgeable about that person and their needs. In the absence of, or isolation from family and - with high rotation of service staff - citizen advocates sometimes become the key person in the life of someone with disability.

While some citizen advocates are only involved as long as it takes to remedy

a particular short term issue, others are involved over a longer term, sometimes for life. Many people with disability who come to the attention of citizen advocacy because of a particular 'crisis' have lives which might in reality be one crisis after another. These crises happen because they are routinely isolated from those who might help them in the way that those of us without disability have help...via family members, neighbours, community groups etc. A very effective way to prevent such things happening, is for people with disability to have someone in their life who is interested in what is happening and who will speak out or take action when necessary. Citizen advocates often note that their presence alone can stop a pattern of neglect and abuse and prevent it from recurring. Crises have a habit of occurring out of office hours. Citizen advocates have a personal, not a professional relationship with the person they are advocating for and therefore the advocacy support they provide is not limited by the hours of operation of an agency.

Citizen advocacy seeks out 'respected and resourceful citizens' because it makes sense that such people are most likely to be influential and therefore effective as advocates in their communities. The connection of an isolated and vulnerable person with a respected advocate can result in other tangible benefits. Good image, good reputation and useful skills have a way of transferring from one person to another when they spend time together. An association with, and being seen as valued, by a person who is socially

valued and well connected in a community, provides outcomes for a vulnerable person with disability which could never be purchased and which even the most skilfully devised and administered human service program would be unlikely to achieve.

Not all people with disability would need or want citizen advocacy, just as not all people with disability need or want other services. Citizen advocacy is important because there are many people with disability whose voices are seldom if ever heard, and who therefore need someone to speak on their behalf. It is particularly important

for those people who are isolated, lonely, and vulnerable to abuse and neglect because they are hidden away from society. These are the people who do not have family involvement. They may never come to an office to negotiate support; they cannot use a phone to report abuse and have no-one independent in their lives to help them seek justice.

For those who are more familiar with the case management approach to organising people's lives, citizen advocacy might seem like a well intentioned anachronism in the company of modern, highly professionalised

services. That would be a mistake. Citizen advocacy is a truly visionary concept, embracing inclusion as a strategy rather than a desirable goal, and being exclusively 'person centred' from its very beginnings 37 years ago. For those who live a life surrounded only by people who are paid to be there, without the personal relationships of family and friends, then the loyalty and protection which comes from having a personal, freely given connection with a citizen advocate is life changing... and sometimes, lifesaving!

# Individual Paid Advocacy

Maree Salzano and Kirsty MacDonald

*Maree Salzano and Kirsty MacDonald are the two Individual Advocates employed by Side by Side Advocacy. Side by Side Advocacy is completely independent of service providers and funded by the Commonwealth Government to provide individual advocacy (at no cost) to people with disabilities living in the Northern to North Western parts of Sydney. This area spans from Hunters Hill, west to Denistone and up to Wisemans Ferry, east to the Northern Beaches and Lower North Shore.*

Individual paid advocacy is a form of advocacy where an independent advocacy agency employs people to stand beside individuals who live with disability, particularly intellectual disability, and who, for a number of reasons, need someone to represent their interests when they are facing injustice and issues of potential harm, neglect, or exploitation.

Each individual act of advocacy upholds the organisation's values and principles. These principles enshrine the belief that all people have inherent worth and value, and should be treated with dignity and respect. As with other forms of advocacy, individual paid advocacy is necessary because of the flaws and failures of the system which leave many people needing the input of a strong and independent voice.

Often an individual advocate will be involved because there is no-one else in the person's life to stand beside them when they are facing a denial of their rights and where the system is exposing them to, or causing, harm and neglect.

*Beth is a young woman who has been moved around nearly 15 times*

*in the last few years. Beth lived with constant insecurity but the one thing she held on to was that she wanted to live on her own and, finally, this opportunity was made available to her.*

***The work is also guided by an unswerving belief that all people have rights and basic needs that should be defended and promoted.***

*Because of the harmful impact of the constant change and lack of control over her life, things did not go well with a particular support worker in her new home. What was a very positive and exciting experience for Beth turned sour resulting in her having to respond to formal, legal complaints by the*

*support person and ongoing court appearances.*

As Beth has no-one else in her life, she was referred to an individual advocate. This person has been standing beside her through the legal processes, helping her to understand and respond to these and – at the same time – working to ensure that she does not lose the first stable home she has known for many years. The advocate has also had to speak up about inappropriate behaviour by the support worker.

She was regarded as a priority for the advocacy agency because she was very vulnerable and unable to overcome the difficulties she was facing on her own. She was also disconnected from her family and had no other meaningful relationship in her life. Beth's situation – caused by a system which was uncaring – will need ongoing involvement. Without the advocate, she almost certainly would have lost her home and become, once again, subject to the whims and incompetency of the service system.

Families often approach individual advocacy agencies on behalf of their sons, daughters or relatives with



situations that they find overwhelming. An individual advocate will work on the basis that a family member can be the person's best advocate, but that at times, it may be impossible for them to act totally from the perspective of the person's interests and needs, because they too feel vulnerable and under stress. In some situations, it is clear that the parents of a person are not in a position to advocate on behalf of their son or daughter.

*Sam has always lived with his now very elderly parents and, following an argument with one of his parents, he was taken away and placed in police custody pending his court appearance the following day. Unfortunately no case was put to the Court about the need to obtain secure alternative accommodation, as Sam could not return home, and he was remanded in the criminal system waiting for a next Court appearance.*

*When the individual advocate met Sam, he was totally overwhelmed by his situation. The advocate set about trying to find him alternative accommodation so that a case could be put to get him out of prison. Because he was in prison, however, the system considered Sam not to be homeless and, despite the protestations of, and representations by the advocate, an alternative accommodation option was not provided and he had to stay in prison.*

*Although Sam eventually spent some time on remand, the advocate, with the support of the advocacy agency, kept up the pressure, speaking up to all the relevant authorities about his level of vulnerability in the criminal justice system, and showing up the inadequacy of the system's overall response. At the subsequent court hearing, this strong advocacy paid off as alternative temporary accommodation was offered and Sam was given bail.*

*While Sam was overjoyed at this, everyone recognises that more work needs to happen over the longer term to find a suitable home for Sam.*

Sometimes, because of the nature of the person's disability and/or because of the complexity and seriousness of their circumstances there is very little scope for them to take any action on their own behalf. In these situations individual paid advocates are guided by listening to other people who know the individual and gaining an understanding of what is important to the person. The work is also guided by an unswerving belief that all people have rights and basic needs that should be defended and promoted.

Beth and Sam are just two of many people whom individual paid advocates have taken on as a priority. Other issues which are taken up by individual advocates include:

- issues in the workplace and places of education
- inappropriate housing and homelessness
- financial hardship, debt and the purchase and rental of goods and services
- segregation and isolation and the potential harm and neglect that arises for a person in these circumstances
- making complaints about the lack of quality of service provision
- applications to the Guardianship Tribunal, review of decisions and financial management processes

- inadequate health care
- supporting people's rights to access formal complaints and appeals processes with bodies such as Centrelink, Housing and the Consumer and Tenancy Tribunal
- conflict with neighbours or service providers.

Individual paid advocacy has to be mindful to:

- listen to the person, or to the people closest to the person
- understand and focus on what is most important to them
- include the person in decision making, or the people closest to them
- work towards inclusion and meaningful participation in the community
- strive to make sure that the actions assist people to gain 'the good life'
- communicate with the person at all times
- act promptly
- avoid compromise and ensure that the advocacy focuses on the needs of the person and not the needs of those who have caused the problem in the first place
- act with trust, loyalty and respect
- represent and speak to the person's positive qualities and potential.



Harness the possibilities for young people with developmental disability in NSW.

Family Advocacy is excited to announce a new initiative that aims to support families that include a child or young person with developmental disability to establish community connections, develop networks and have skills and ideas to direct any necessary supports.

**Planning – Skills – Networks – Community**

Email: [info@resourcingfamilies.org.au](mailto:info@resourcingfamilies.org.au)  
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[www.resourcingfamilies.org.au](http://www.resourcingfamilies.org.au)

# Systemic Advocacy - Creating Positive Change Within the 'Big Picture'

Therese Sands

*Therese Sands, Executive Director, Leadership Team People with Disability Australia (PWD).*

As its name suggests, 'systemic advocacy' is about advocacy at the systems level rather than the individual level. It's about changing systems that negatively impact on people with disability and as a result, it can create change for all people with disability.

Systemic advocacy is often informed by trends identified through individual advocacy and via members and constituents of a systemic advocacy organisation. It can address the individual issues that continually arise by creating larger changes in the system.

Key aims of systemic advocacy can include:

- the promotion of social justice for people with disability
- the promotion of the contribution and potential of people with disability
- the achievement of positive changes to those structures, policies and practices that exclude and discriminate against people with disability and put them at risk of abuse and neglect<sup>1</sup>.

Laws, policies or procedures which create attitudinal, social, environmental, economic and communication barriers are the target of systems advocacy.

It is a long-term endeavour, requiring commitment, strategic planning and constant review. Systemic advocates need to respond to changing circumstances, such as Ministerial or legislative changes, and work strategically and often over many years. Many strategies are used to achieve change, such as:

- parliamentary processes
- legislation and legal action
- collaborative partnerships
- awareness raising
- research and data collection
- representation on committees
- United Nations (UN) monitoring processes
- meetings with Ministers and senior government officials
- preparation of Position Statements for sector endorsement.

Systemic advocacy can often be a frustrating exercise, particularly when positive change is reversed, when concerted advocacy campaigns do not result in change or they result in piecemeal reform. This can occur when governments are strongly focused on implementing their own policy agenda and dismiss advocacy efforts.

A current example of this involves the 2006 decision by the NSW Government to reverse its 1998 decision to close large residential institutions in NSW with a promise that by 2010 all institutions would be closed. To obtain government commitment to close institutions, advocates had worked hard lobbying the government of the day. Throughout the past 12 years, advocates have continued working with and pressuring government during the ups and downs of its devolution of institutions. In 2006, however, the then Minister for Disability Services, John Della Bosca, changed accommodation policy in NSW from one focused on community living, to one focused on building a new generation of residential institutions.

As a result, systemic advocates had to consider a new plan of action to address this government policy reversal. Since then, systemic advocacy organisations have concentrated on presenting arguments to the NSW Government both individually and collectively, on seeking community and service provider support for our views and on gradually placing more pressure on the NSW Government to respond positively.

This approach represents an underlying principle of systemic advocacy – to provide all available options to the other party, in this case the NSW Government, before escalating actions to another more adversarial level. In other words, systemic advocacy aims for a collaborative approach to create change, and only when this is not possible will advocacy actions gradually become more adversarial. This is an important principle because it highlights that systemic advocacy is not necessarily combative, which is a common misconception. Ideally, systemic advocates can work in partnership with many stakeholders to create positive change. This principle, however, also recognises that a role of systemic advocacy is to be 'fearless' in the face of opposition and that adversarial action in some cases will be the only option available.

In the current example, and after nearly 2 years of ongoing advocacy actions by a number of organisations, People with Disability Australia (PWD) very reluctantly and as a last resort, filed an application with the NSW Administrative Decisions Tribunal (ADT) formally seeking a review of

1. These systemic advocacy aims are taken from the Strategic Plan of People with Disability Australia, *Forward to Our Future 2007-2010* available on <http://www.pwd.org.au/archive.html>

the Minister's decision to continue to operate three institutions - Grosvenor, Lachlan and Peat Island Centres - contrary to the requirements of the *Disability Services Act 1993* (NSW) (DSA). This action was supported by many NSW representative and advocacy organisations, including Family Advocacy, and is currently still proceeding through the legal process.

Systemic advocacy needs a clear framework to be able to assess what

is positive change for people with disability and to identify outcomes to strive for. This could be legislation, such as the DSA or the *Disability Discrimination Act 1992* (Cth).

Since the Australian Government ratified the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) in 2008, this has increasingly become the framework for gauging the status of people with disability in Australia. Given the

United Nations Covenant affects all jurisdictions in Australia, it provides a powerful tool for coordinated and consistent systemic advocacy efforts throughout the nation.

Along with all forms of independent advocacy, systemic advocacy is critical to protecting and safeguarding the rights of people with disability.

## An example of a systems advocacy action

### The issue

People with vision impairments are unable to make a secret vote at State or Federal Elections

### Why?

The law states that voting is made on a printed ballot paper that you need to be able to read. Therefore someone else has to make the vote meaning it is not secret and independent.

### The Solution

The formal procedures for voting needs to change.

### Strategies

An individual could lodge a complaint with the Australian Human Rights Commission (AHRC). This may solve the problem for an individual but not for all people affected by the current law and procedures.

Systemic advocacy organisations have been lobbying Members of Parliament through letter writing, submissions to Parliamentary Inquiries, meeting with Government Ministers and representing the views of people with disability to the Australian Electoral Commission.

The advocacy has used anti-discrimination legislation, international obligations and evidence from individuals. Other organisations have been invited to be part of the lobbying.

### The result

Although the lobbying needs to continue, The Australian Electoral Commission has responded with a trial of electronic voting procedures.

*family*  
A D V O C A C Y

If undeliverable, return to:  
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## Family

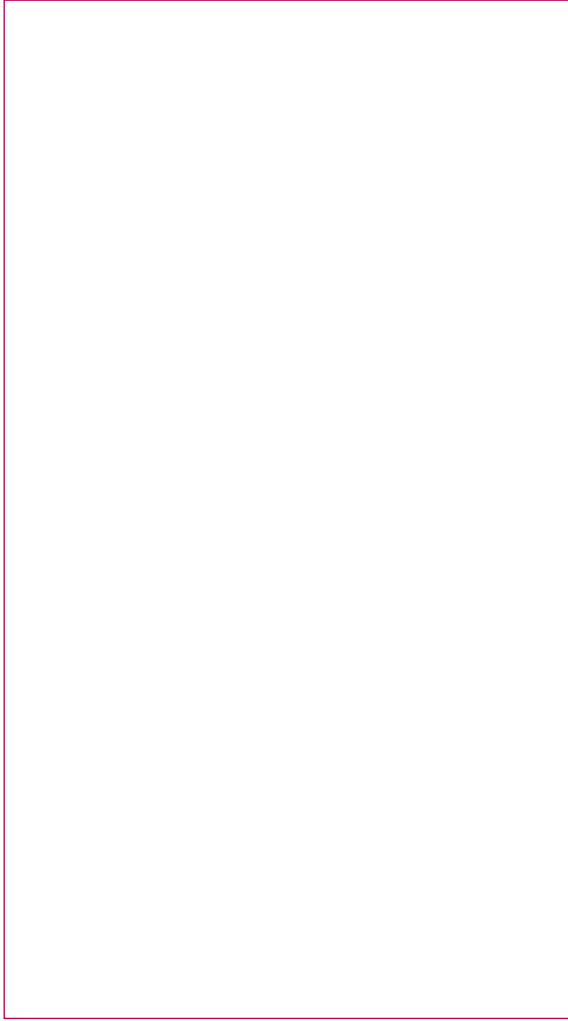
Groups which actively and powerfully shape society and within which there are unique individuals who share challenges, changes, struggles, failures, and successes... and sometimes dreams.

## 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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