

Families for Change

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

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The Ties That Bind

family
ADVOCACY

There is such truth in the saying “it’s not what you know...it’s who”. Time and again, good things happen because of a connection between two people - a job is found, a lunch date made, a shared interest is discussed. Perhaps the two people are long term friends or perhaps they’ve just met, but they have a connection around a shared commonality, idea or person and this is what has brought them together.

The theme for this edition of Family Advocacy’s journal is ‘networking and connection’ and the importance of these two elements in terms of what they can bring into a person’s life. Many benefits spring from the people we are connected to – some practical, others much more personal. The practical benefits can be as simple as having someone assist you perform a task, lend you something, drive you somewhere. On a more personal level, having people in our lives makes us feel valued, secure, worthwhile...it elicits a feeling of ‘someone knows and cares about me and is interested in me’. Therefore building connections with others is vital to the development of a sense of self worth, self esteem and simply feeling good about oneself.

The people in our lives can be many and varied and the level on which our connection with them sits, also varies. There are the people in our neighbourhood to whom we wave as we drive past them raking leaves in their front yard. We don’t know their names, but we recognise them and say hello. There are the people we see regularly at the shops we frequent, who say “How are you? The rains’ been good!” Not a deep interaction, but a nice one just the same. These people are really only acquaintances, not friends, but they still play a role in contributing to the fabric of our lives

and keeping us attached and connected to our community.

Then there are the significant connections. These relationships are generally with immediate family, close friends, work colleagues or neighbours. These are the quality relationships that provide the stability and security that we all need to sustain us. These are the connections that can act as a buffer to all the challenges that life can throw at us. These significant relationships wrap around us like a cushioning blanket, providing warmth, comfort, support, security and protection when we need it.

“...building connections with others is vital to the development of a sense of self worth, self esteem and simply feeling good about oneself.”

We would all recognise the value of these quality relationships and probably at times take them very much for granted. Being connected and deeply rooted in our families and communities allows us a level of flippancy with a somewhat intangible ‘something’ that if lost, would probably devastate us to the core of our being.

Being in and of community is no small thing and for people with disability it often takes conscious intent and deliberate action to bring it about. Relationships and connections with others are sometimes elusive. Networking and putting ourselves ‘out there’ takes a level of skill and confidence not possessed by everyone. For some, this networking and relationship building will require

facilitation and assistance to bring it about. In this edition of Families for Change, Wendy McGlynn shares one strategy she employs to assist her son Mark connect with others. Ingrid Michalowsky and her husband have recognised that they must be the conduit through which other people are brought into their son’s life. Wendy Davies shares a small insight into the importance of networking with people outside of immediate family, and the good things that can come from it. In his article ‘The Big and the Small’, Ric Thompson explores what we mean by community and ways of identifying opportunities for connecting and networking that might otherwise be missed.

The term ‘networking’ has become a catch phrase of the modern day and it is easy to dismiss it as a strategy that only the business sector would use in the quest for new contacts. We mustn’t lose sight of the broader meaning of the term and the opportunities it can create for people with a disability.

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Networking – The Big and the Small

Ric Thompson

Ric Thompson is the Coordinator of Inclusion Works, a small community building agency in Townsville, Queensland and is a strong advocate for inclusive communities. As part of his work, Ric explores with individuals, families, services and the wider community how partnerships/networks can be fostered and maintained, resulting in a better life for all.

Over time I have welcomed the opportunity to learn in the presence of great teachers – including Professor John McKnight from Chicago, USA and Neil Barringham from West End, Brisbane, Australia.

John McKnight was to present a three hour workshop at Victoria University, Burwood, Victoria in 1986. His plane was late, so it became a two hour workshop! Despite this, some 20 years later, my work has been significantly influenced by that two hour presentation. (Who said that training doesn't have a significant long term impact?) One of John's major contributions was his definition of community. John defined community as: *"the social place used by family, friends, neighbours, neighbourhood associations, clubs, schools, civic groups, local businesses, churches, ethnic organisations, temples, local unions, local government, local media etc"*.

This definition is seen as an associational definition of community, whereby within each sub-group there is a social place where there is a presence of commonality, of shared interests, whether it be a family, street, a Church, a club or even the local Union.

This definition challenges us in a number of ways. Firstly, it expands our definition of what we previously thought community comprised of, and secondly, it exposes us to our own fears and uncertainties when it comes

to connecting with those wider groups that we may wish to avoid. The full extent of John McKnight's definition became evident when, with the help of the Townsville based Community Information Centre, we identified over 180,000 networking opportunities.

"....some of the most powerful and relevant networking opportunities already surround us and exist with others already known to us."

When you have this sort of framework you are certainly encouraged to think **big**.

Neil Barringham works in Brisbane and is equally important and influential in his work with communities. Neil coordinates a small service, 'A Place to Belong'. Neil's work has provided much valued leadership in recognising the value of working at the 'grass roots' level, the importance of starting small and with the local community, where people are close to each other.

Neil's work when it comes to networking, commences within the immediate centre of one's community - being one's self and others known to you. Neil's work constantly reminds us that some of the most powerful and relevant networking opportunities already surround us and exist with others already known to us.

Neil also reminds us that networking opportunities for people with a disability and their families exist:-

- Within existing community networks, such as clubs etc.
- Within the individual's (or families) existing networks.
- Within a support worker's own networks.
- Within the relationships of colleagues, friends and their networks.
- Within other networks, for example who are the 'movers and shakers' within your community, such as Local Councillors, business leaders, Church leaders.

Neil's focus reminds me of a workshop I ran in a small rural community in North Queensland. It was facilitated by the Mayor with over 100% attendance (in other words, people turned up who weren't invited). It comprised of representatives from a smorgasbord of local community groups. The meeting was a great success, and in walking back with the Community Development Worker she sought advice on where to go next. My answer was simple. Put a white board on your wall directly in front of your desk, and write the names of the people present (not their groups/associations), as communities are comprised of people and it is people we need to have conversations with. Margaret Wheatley, a social activist comments on the importance of these

“social change begins with a conversation”.

conversations when she says “social change begins with a conversation”. The next task for the Community Development Worker was to visit those individual people and to seek a greater understanding of who they were.

The poverty of experiences within the lives of many people with a disability

and their families has also resulted in limited networking opportunities. If you’re not in community, you can’t get to know community nor can it get to know you. This is made even more complex when the disability support industry accepts the responsibility for not just replacing community but replacing community relationships in the lives of individuals with a disability. Once again the question needs to be asked – “Whose needs are being served here?”

John McKnight reminds us of the power and potential of community. Neil Barringham reminds us that the more formal and bureaucratic our relationship systems become, the more we distance people from people.

John McKnight and Neil Barringham invite us to consider the networking capacity of community and the opportunities that come from within, helped by how we define community - both the big and the small.

A Good News Story!

Wendy Davies

Wendy Davies is a parent who lives in Queensland. Wendy attended a conference in February this year, run by the Community Resource Unit (CRU) in Brisbane. The article below was written shortly after the conference, as Wendy reflected on some of the key learnings that had taken place for her while there and what she has been able to achieve because of them.

I thought you might like to hear about my daughter, Emma and her good news which only happened this past month...

After going to the CRU Conference and hearing all the positive and inspiring things people were doing, I decided that my mouth (that used to get me into so much trouble at school, because it was always open) was now my biggest obstacle as I felt safer keeping it shut! So when a mother at swimming training asked me how my daughter was going, I told her that Emma was doing volunteer work 1 – 1 1/2 hours away by public transport, and that she needed to get some work in her local community, which was what I was focusing on now.

Within a week, this mother told me, almost apologetically, that she had approached her daughter’s school library which was always calling for parent volunteers, and asked them if they would give Emma a trial to see if she could help out. She hoped I didn’t mind, and if not, the Librarian was happy to talk to us and arrange

a time for Emma to come along and meet them.

So I took Emma along and she has now completed three hours work at the Library, learning to put away books, and she is going back on a regular basis every fortnight. The other bonus was that this wonderful Mum suggested that if we arranged for Emma to finish work at 3pm, then she would pick Emma up and take her to swimming training with her daughter.

After the first day at the library, and after swimming training, we took Emma out for dinner to celebrate her new job. She was as proud as punch, and wanted to ring her brother and sister about her newest achievement. The lesson that we don’t have to do it all ourselves has been brought home powerfully to me, and I know that I need to continue opening my mouth about Emma’s dreams.

Another person who is as proud as punch is the Mum who got her the job, and she is now talking about

“...the lesson that we don’t have to do it all ourselves has been brought home powerfully to me....”

Emma getting a paid job with the experience she gains at the library. So now there is another person involved in Emma’s life, daring to dream of a good life for our daughter.

‘Sometimes when I consider what tremendous consequence come from little things... I am tempted to think... there are no little things.’

(Bruce Barton)

Sowing the Seeds for a Good Life

Ingrid Michalowsky

Ingrid Michalowsky is a designer who, together with her husband, has two children aged 6 and 8 years. Their son has severe autism and high support needs. They are always looking for opportunities to provide their children with connections to their immediate and broader communities.

I have always loved coming from a relatively large family.

My older brother once quoted to me the well known saying that 'it takes a village to raise a child'. I realise now that I, as a daughter raised by a single mother and three older siblings, was that child, and that my family was my village.

I don't think I ever really understood the saying until now. I certainly could not have anticipated how it would apply to my children, particularly my youngest, who has a disability. Initially I believed that my son was my responsibility alone, and that I would need to be by his side to protect him for ever more.

My view has since changed, and my challenge is now to change the views of certain members of my family, and of the strong community to which we belong. My role and my husband's role will be no different to that of any other parent, to nurture and protect our children, but we will also need to assist our child to create a fulfilling and meaningful life. For this we will need help - help from family, help from friends, help from the community, and help from business. We will need networks, networks that will support both our son and our family. We can't do it alone.

We already have extensive informal networks which play a large role in our day to day life. My sisters-in-law, for example, will often ring on the weekend and offer to take our son to watch their children's soccer matches with them. They will collect him and take him to the game. He may watch, he may not, but the outcome is one that is positive for all. He is out in the community with people whom

he cares about and who care about him, doing a regular activity that is meaningful. It is opportunities such as these, opportunities that tap into peoples' existing day to day lives that best help us to achieve our goals for our son.

For our family, success lies in our son being included into existing activities and routines with no great extra effort. He doesn't speak, but it is easy to tell if he has had a good time. He will be smiling from ear to ear when he runs into the house, and on a return visit will take the person by the hand and head for the front door in anticipation.

For my son's recent sixth birthday, we held an extraordinarily large party for him. Not because the other children were his 'friends' in the true meaning of the word (he has only ever been invited to play at a 'friend's' house once), but because the children's parents are our friends, and my husband I share the view that it is our social responsibility to expose our son to as many friendship and life opportunities as possible. We also believe that it is our social and moral responsibility to give our son the chance to show people what a wonderful, loving and fun person he is. First and foremost he is a person, and secondly, an individual with a disability.

There will always be people who can only see my son's autism. However, there are a vast number of people who, if guided to open their hearts and eyes, will see that the autism is only a small part of who he is.

It's about someone greeting our son in the street and his face lighting up with recognition. It's about him turning up

to watch his cousins play their weekly soccer games, and people recognising him. The first week they stare as he runs the full length of the field 20 times over, the second week they stare a little less, the third week someone greets us, and by the fourth and fifth weeks we are just one of the crowd. It's about him being invited back to the home of one of the plethora of 'friends' we invited to his birthday party. It's about people seeing the person, not the autism. It's about allowing his soul to shine brightly.

"...we will also need to assist our child to create a fulfilling and meaningful life. For this we will need help...."

Part of our role in creating these networks is to recognise that special quality in a person which will allow them to 'see', to want to 'see', and to want to be part of our son's life. Our role is to ask and to create opportunities which allow people into our lives, and to support both parties for success.

I use to find it hard to ask for help, because I thought that I was asking people to do me a favour. Now I see that it is me who is doing them the favour. I am asking them into my son's life and into ours. It is not perfect, and it is often a little messy, but it is filled with real life, with love, and with a sense of achievement and optimism. My children are delightful, special people who can offer a great deal to those willing to see.

'It's about whom you know, not what you know....'

Little Things Mean A Lot

Wendy McGlynn

Wendy McGlynn currently supports Family Advocacy by assisting with presentations at face-to-face workshops. A past employee of the organisation, Wendy now enjoys following her interests, which include mosaics, travelling with her husband and spending time with her family and friends. In this article, Wendy considers the importance of keeping connected through seemingly simple things, such as the sending of cards.

A few months ago, my husband John and I became grandparents for the first time. This marked the beginning of a new chapter of our lives, and so we were delighted to receive cards congratulating us on becoming grandparents.

Who doesn't like receiving cards on special occasions? Often it's for a birthday, but whatever the reason, it reinforces the connection between the sender and the receiver.

Connecting with people is important. The relationships – or lack of relationships – in our lives, impact on our self-worth and sense of purpose. I think of my friends and family members more often than they would imagine; however, it's only when I follow through with a phone call, email, invitation or card that they get to know that I'm thinking of them.

Connections are just as important for our son Mark. Mark is now in his thirties. He has always remembered the birthdays of key people in his life. He'll often talk about the birthday for weeks beforehand. Sadly, however, there have been too many times when those people, whether friends or family, haven't known that Mark is thinking of them on their special day. This is because, without assistance, Mark's disability stands in the way of him following through. Yet it's even more important in Mark's case that he follows through, as he has few relationships and can't easily pick up the phone and wish someone a happy birthday.

And yet it was no easy task to convince the people who have supported Mark

over time that it's worthwhile helping Mark follow through on birthdays and other occasions. In fact, I believe it is vitally important and to neglect this aspect of Mark's life is to deny what he has to offer to others in terms of affection and caring.

“Connecting with people is important. The relationships – or lack of relationships – in our lives, impact on our self-worth and sense of purpose.”

This means recognising that the birthday or other occasion is coming up in time to do something about it (a birthday book and calendar are important here). It's not just a case of ensuring that Mark buys a card, either, as more than once I've discovered unsent cards lying on top of, or in the chest of drawers in his bedroom, well past the significant date.

While Mark is clear on what he wants to say in cards, he often needs help with the spelling of words, so it's important that someone is involved at every step – and a card is far more likely to reach its destination if someone else writes the address! Also, in his enthusiasm to get the card into the mail, he has been known to mail the card without the stamp, so it's important that he is assisted to complete the whole task at the one time.

When people receive cards from Mark, they sometimes give him a call to say, “thank you” and have a chat, or family members will phone me to tell me how pleased they were to have received a card.

I remember assisting Mark and his friend give a wedding card to two former support workers on the occasion of their marriage and hearing later that the gesture brought tears to the eyes of the bride. The giving of the card was a simple gesture, but one that followed through on the good wishes that Mark and his housemate had for that young couple.

Little things mean a lot.

The Odyssey... 
a journey of enrichment and possibility

25 & 26 October 2007

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Call Family Advocacy today
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Tel: (02) 9869 0866
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Email: conference@family-advocacy.com

Resources from the Inclusion Collection

Below is a selection of resources about 'networking and connection'. You can order articles, books, videos and kits from the Inclusion Collection online at www.family-advocacy.com or by phone on (02) 9869 0866 or 1800 620 588 (for non-metropolitan callers).

Circles of Support

File 10736

Michael Peterson outlines support initiatives that have been successful in assisting people with disabilities to participate in their community. An important strategy is the 'circle of support': friends, family and community members gather together around a person with a disability to plan and support them to attain a more community centered lifestyle.

John Deere and the Bereavement Counsellor

File 11091

This article discusses how service technologies have the potential to impede progress, rather than accelerate it. The example used is 'bereavement counselling', a service which weakened the effectiveness of family and community support in times of mourning. This article questions our growing reliance on professional services for support, and demonstrates how such reliance is developed not in response to need, but as a by-product of development.

Promoting Inclusive Services for People with Intellectual Disabilities

File 10524

Mike Steer gives an overview of research on human service systems, policy development and government programs for people with disabilities from the Centre for Human Policy, Syracuse University, and links this research into what is happening at a bureaucratic level in Australia. The research discusses the limitation of service systems and that they cannot and should not be constructed to provide everything, because when this happens they become 'disabling systems'. The article also focuses on the importance of strengthening or creating community and informal networks, the importance of creativity and having clear principals that aid the movement beyond where we are today.

Family Support Networks

File 10208

These notes were taken by Wendy McGlynn, a parent who attended a seminar on Family Support Networks by Bruce Uditsky, an educator who has worked extensively with families, individuals with disabilities and organisations. Uditsky encourages families to start building up networks while their child is still young, and offers suggestions on how families can become involved in their community. He emphasises that people with disabilities, who have multiple relationships in their lives as children, have a greater possibility of developing their own networks as adults.

Social Integration and Friendship

File 10119

Jeff Strully, a parent leader from America, states that "The lives of all people in our community are measured by our relationships and connectedness to a place called home, where people want to be with us because they are our friends". Human service systems disconnect people with disabilities from their neighbours and communities, and the community comes to have a distorted view of their needs. It becomes harder and harder for families to envision a community based future for their son or daughter. Strully emphasises the importance of friendships which help to ensure that all people can become active members of the community. He provides examples and concludes that it is time for all of us to work towards connecting people with disabilities to a network of support.

Friends

Book 3076


This manual is for anyone who is interested in supporting a person with disabilities to widen his or her circle of relationships and develop deeper friendships. It describes the processes used in the 'Friends Project', a one year project designed to study and develop methods to support people with disabilities in establishing friendships with non disabled people in their communities. This manual provides concrete suggestions about relationship building and real life examples.

25 & 26 October 2007

Mercure Sydney, 818-820 George Street Sydney Australia

www.family-advocacy.com

The Odyssey...



a journey of enrichment and possibility

Would you like to hear how people with developmental disability can:

- live a rich, varied and secure life?
- be open to the possibility of making friends and developing relationships beyond family?
- experience positive learning opportunities?
- be recognised as part of the wider community?
- have constructive meaningful leisure time?
- have a place to call home?

Family Advocacy's first national conference, *the Odyssey.....a journey of enrichment and possibility* tracks the potential for all these things throughout the lives of people with developmental disability.

This two-day Conference, to be held in Sydney on 25th and 26th October 2007, will provide an exciting opportunity to hear about **real life experiences and examples** from **inspirational** local, national and international speakers. Additionally, participants will have lots of opportunity to interact with speakers and other people attending the Conference to further share ideas and experiences.

You may be a family member, friend of, or support a person with developmental disability. You may work in the area of disability or you may be interested in human rights and social inclusion. If you want to find out what is possible, then this Conference is for you!

We want to inspire positive change in the lives of people with a disability, through giving you ideas, contacts and practical examples that can be taken away and used to make that change a real possibility.

*Don't miss out Call Family Advocacy **today** for further information on how to register or look on our website at www.family-advocacy.com*

Tel: (02) 9869 0866 or freecall 1800 620 588 (NSW only)

Email: conference@family-advocacy.com

A limited number of sponsored places will be available for people with disability and/or family members. Please contact Family Advocacy directly for more information.

Developmental disability covers intellectual disability, autism, cerebral palsy, spina bifida, brain injury occurring in the developmental period and multiple disability.

Family Advocacy is an NSW wide, not for profit advocacy organisation, concerned with the needs, interests and rights of people who have a developmental disability. Its aim is to achieve positive social roles for people with disability through the development of advocacy by families and by strengthening the knowledge, role and influence of the family.

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A D V O C A C Y

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We're on the web!
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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

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