

# Mamrebillia

Autumn 2011

## A word from the Director

Dear Friends,

Welcome to this edition of Mamrebillia, and the theme of VALUED ROLES.

I am very excited to see the various contributions in this edition and how others are so willing to share their wisdom, stories and learning. We all hold roles in life – family members, parents, partners, children, siblings, grandchildren, students, employees, consumers etc. What is important is how we view our own contributions and therefore recognize our own value, and how then are we valued by others.

For people who are vulnerable it is essential that they too are recognized in the roles they hold – in our families, in our neighbourhoods and in our communities – as equal citizens and equal contributors to our world.

I love Stephen's story in this edition. Stephen has always loved keeping lawns and gardens maintained, even as a young boy. If you are like me, I love my garden and lawn to look lovely but I have no talent in this field. Yet, I have great respect for people who feel very passionately about the environment, and take the time and energy to maintain surroundings. Stephen is now a small business owner who has negotiated lawn mowing contracts. Developing your own business takes time, energy and commitment. Stephen is a credible and professional service provider. This is another very important and valued role he holds in the community.

For some time now I have been a



fan of Eleanor Roosevelt and have admired her contribution towards the International Declaration of Human Rights and to Human Rights in general. Feeling valued in the world means to belong and to be respected as an equal human being. How do we ensure that we belong? I think Eleanor sums it up beautifully when she says:

"Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

I hope you enjoy this edition, and I hope you and your family have a safe and relaxing Easter time. Take care of you and yours,

**Rachel Johnson**

### *Inside this edition:*

<i>Acceptance and Belonging</i>	<i>pg 2</i>
<i>Tribute to Dr Wolf Wolfensberger</i>	<i>pg 3</i>
<i>National Disability</i>	
<i>Insurance Scheme</i>	<i>Pg 5</i>
<i>Mamre's inspirit Program</i>	<i>pg 7</i>
<i>Work, Study and other valued roles</i>	<i>Pg 8</i>
<i>Steven's story</i>	<i>Pg 9</i>
<i>SRV and valued roles</i>	<i>Pg 9</i>
<i>Awareness—spirituality for everyone</i>	<i>Pg 11</i>

Welcome to the latest edition of Mamrebillia! This edition explores ideas and thoughts around the theme of valued roles. It is our hope that the articles are thought provoking and informative. If you have any feedback concerning this edition, please don't hesitate to contact me at Mamre on **3622 1222** or by emailing [peter.vacca@mamre.org.au](mailto:peter.vacca@mamre.org.au) Have a wonderful Easter filled with hope, faith and love!

**Peter Vacca**

# Acceptance and belonging: *the helpfulness of being in valued roles*

Jane Sherwin

*Jane Sherwin is a Queensland based consultant who has been involved in the lives of people with disability since the late 1970s. She is well regarded for her teaching and writing and has worked in government and community services in a range of management and direct service roles. Jane has been involved in social change efforts, particularly through her roles with Community Resource Unit Inc (CRU), including as Director of CRU until mid 2007. Jane is a Senior Social Role Valorisation (SRV) Trainer, having participated in the teaching, learning and application of*

*SRV since the early 1990s. Jane finds SRV theory helpful in understanding how society and human services work, and in thinking about how to progress issues for people with disability. Jane is also a member of the Australian & New Zealand SRV Group.*

One of the strongest wishes that a parent can make for their sons and daughters, with or without a disability, is that they are happy and fulfilled in what they do and who they are with. This is at the core of wanting acceptance. Without acceptance, the pain of rejection is felt strongly by the son or daughter with a disability and by those who love them. Finding ways to protect against the likelihood of rejection and increase the possibilities of accepting relationships is important.

Feelings of acceptance come from being acknowledged as someone who is intrinsically worthwhile and/or having characteristics that are seen as worthwhile. This could be as big as being in a role that allows someone to contribute to society, or it could be as small (yet no less important) as being admired for one's way of being in the world. Belonging is such a fundamental human need, and being accepted brings a sense of belonging. The majority of people need and want to belong to all sorts of groups and places such as families, friends, neighbourhoods, workplaces, clubs, and interest groups. Belonging and feelings of deep acceptance are like being 'home' in a relationship. There is a sense of comfort within the relationship, and a sense of being safe and secure.

Acts of acceptance and their cousin, acts of tolerance, towards people who are marginalised, bring out the better qualities in each of us. These acts come from private thoughts and personal actions, but the benefits are more public: they lead to caring and compassionate communities. They lay judgemental thoughts and behaviours to rest. They bring peace between people.

Having a life of meaning and rich ordinariness is a central goal of SRV, and being in valued roles is one way that helps achieve this. The application of SRV principles helps us to assist ordinary citizens enact acceptance and tolerance.

How might valued roles encourage acceptance in the community? There are five things for family members and people with disabilities to think about.

1. Acceptance comes from a changed perception about people with disabilities. The deeply embedded prejudices about people with a disability come from stereotypes about people with disabilities.

These stereotypes are the negative roles that people with disabilities have been weighed down with throughout the ages. They include the stereotypes of children forever, worthless, useless, can't learn, sick, a drain on our society. Therefore, SRV helps us understand that we need to challenge the preconceived ideas that ordinary citizens have about people with disabilities. We can do that in two ways: firstly, don't reinforce the ideas by even unwittingly treating people as if they are children forever, worthless, useless, and so on. Secondly, we can do this by supporting people to be in valued roles that show people in a positive light.

Changing perceptions is called 'popping people out' by John McGough, an American man who has Down Syndrome. He says that when people see him and his Down Syndrome features, they expect him to be a certain way: like other people with that syndrome, to be placid, to like music and animals, to never grow up, to never have intimate relationships, to be a burden on the family. However, when people discover that he is a loved family member, a member of his local church choir, a talented artist who has exhibited and sold paintings, a part time worker at a local grocery shop, a best friend of someone who is also a musician, and a member of a band, John believes that they get 'popped out'. They expected one thing based on preconceived ideas and stereotypes; they discover another. This challenge and discovery is because John is in valued roles.

2. Being in valued roles that are related to interests or talents reinforces the similarity between people, rather than emphasising what is different. It follows then that it is helpful to assist the person to find roles that are truly authentic for them and which build on the gifts they bring to the world.

3. Think roles, not activities. If ordinary citizens see people being 'occupied', 'programmed' or 'minded' in the community, then they are likely to assume that that is all they can cope with, and that they need a special worker to be with them

to do those things. This squeezes out the possibility of an ordinary citizen being in an accepting relationship with the person.

4. Use ways that are typical, ordinary and valued to meet the needs of your son or daughter, or yourself. Truly valued roles only occur in ordinary life. These are the roles related to home, work, relationships, study, hobbies, civic duties, and being generally out and about. Reflect on questions that start with 'How does anybody else of a similar age, gender and culture ...?' This will give clues to more specific strategies that assist someone to be in a valued role. So depending on what the desirable future of the person might be, the question could be such as: 'How does anybody else of a similar age, gender and culture tend to find flatmates?'; 'How does anybody else of a similar age, gender and culture typically spend a meaningful day?'; 'What are the range of valued ways that anybody else of a similar age, gender and culture celebrates their 18th birthday?'

5. Pay attention to image. The messages that people send to the world about who they are come from a variety of sources such as how the person looks, who the person spends time with, their possessions, and where and what they spend their time doing. This means helping people put 'their best foot forward'. This also means paying attention to those things that are likely to lead to rejection by others, such as poor social habits or an offensive smell.

SRV does not offer any recipes for acceptance. What it does do is help us think

about those things that are likely to increase the possibility of acceptance and belonging. By paying attention to these things, it is likely to bring out the best in all of us: emphasising the characteristics of the person as a fellow human being with feelings, hopes, interests and gifts; assisting them to have access to better lifestyles; and bringing forth acts of acceptance in community members.

Reprinted with permission from Family Advocacy.

The citation for this article is:  
Sherwin, J. (2008) Acceptance and belonging: the usefulness of being in valued roles. Families for change. 3, 7, 2-3



## The World Wide Disability Community has lost a significant ally and advocate:

A Tribute to  
Dr. Wolf Wolfensberger  
(1934-2011)



Born in Mannheim Germany in 1934, Dr. Wolfensberger was an American academic who influenced disability policy and practice in the United States and throughout the world through his development of Social Role Valorization (SRV).

Much of his work has been concerned with ideologies, structures and planning patterns of human service systems, especially concerning persons with intellectual disabilities and their families. He authored and co-authored more than 40 books and monographs, and wrote more than 250 chapters and articles. His books *Changing Patterns in Residential Services for the Mentally Retarded*, *The Principle of Normalization*, *PASS* and *PASSING* are probably best known. His writing has been translated into 11 languages.

Dr. Wolfensberger was the foremost propagator of normalization in North America and was the originator of Citizen Advocacy and Social Role Valorization. In 1999, Wolf Wolfensberger was selected by representatives of seven major mental retardation organizations as one of 35 parties that had been the most impactful on mental retardation worldwide in the 20th century. The Journal "Exceptional Parent" recognised Wolf's work as "one of the great 7 Contributors to the lives of people with disabilities, along with Salk and the polio vaccine, Americans with Disabilities Act and the invention of the wheelchair".

In 1998, I was fortunate to attend an 11 day event in Brisbane with Dr. Wolfensberger and his associate Dr. Susan Thomas – the event was hosted by Values in Action and CRU. During the event it became apparent that very little would slip past him whether it was a joke from the audience, an opportunity for humour or information that was being shared that required further clarification and interjection by Dr. Wolfensberger. For a man who was so highly regarded worldwide he was a gentle and humble man who had the upmost respect and honour for all human life.

We have lost a significant leader in our field. Wolf was a man who remained true to asking the deeper, bigger more profound questions around people who are vulnerable at the heart of our human communities. He was radical. He had courage and he was not afraid to say what needed to be said but he did so with gentleness and sensitivity. There will be thousands of people with disability, their families and sector workers who will be devastated by the loss of Wolf. Mamre sends our love, thoughts and prayers to his family and his associate Dr. Susan Thomas.

*Julie Johnson.*

## What to do when things go wrong with your support from Mamre

*In the interest of keeping families informed and up to date in regards to Mamre policies, we are continuing to publish extracts from our Family handbook. In this edition, we are putting the spotlight on our complaints mechanism and explaining how you can raise an issue in relation to your service at Mamre.*

### Policy Statement

Mamre will consider all complaints seriously and will act promptly, fairly and confidentially with the involvement of the family to rectify any poor service. Mamre aims to redress any hurt caused to individuals and families and improve its overall performance by learning from these complaints.

### Rationale

At times, Mamre may make mistakes or provide poor service. This is not by intention and the sooner Mamre realises its mistake, redresses any hurt and improves its service the less likely other families will be affected.

### Procedure

If a family is not satisfied with Mamre's service, Mamre asks them to act promptly and talk to:

the person who has made the mistake or provided the poor service; or  
the supervisor of the service, Team Leader or Director; or  
any member of the Governance Board (See [1.1.1 Governance Board](#)) who will then inform the Director;

If a family feels uncomfortable about making a complaint on their own, Mamre encourages them to use an advocate. (See 3.5 [Advocacy](#).)

The staff member or Board member contacted will first check if the family wants to resolve the issue informally or to make a formal complaint and will act immediately to resolve the complaint.

If the staff member involved cannot resolve the complaint, he or she will inform his or her Key Worker or supervisor within **twenty-four (24) hours** of the original complaint.

*Cont on page 4*

Cont from page 3

If the Key Worker or Co-ordinator is unable to resolve the complaint, he/she will contact the Team Leader.

If the complaint is formal, the Team Leader will:

- treat the complaint as an incident (See [3.14 Incidents](#));
- meet with the family as soon as practical for both parties;
- develop a resolution to the complaint to be signed by all parties, if necessary;
- inform the Director of the complaint and the resolution; and
- Follow up on the agreed actions **within twenty-eight (28) days**.

The Director will keep a copy of all formal complaints and follow-up actions on the Incidents Register.

If Mamre fails to address the complaint satisfactorily, families can contact Disability Services on (07) 3224.7179 or [complaints@disability.qld.gov.au](mailto:complaints@disability.qld.gov.au) for DS funded services or (07) 3405 3838 for HACC services.

The Key Worker will provide this information to all families at the commencement of support and every year after.

*If you have any questions about our complaints policy, please don't hesitate to ask your Keyworker or ring the Mamre office on 3622 1222.*

**FREE!**

### **Electronic Wheelchair lift for a Vehicle**

**Model: VL955U3144**

**12 months New!**

**Would suit larger Vans including:  
Mercedes bus, VW Multivan, Toyota Hiace  
Commuter or Toyota bus**

**The owner no longer requires this device and would love another family to receive this gift for free without the struggles of needing to raise funds for themselves. They would only appreciate the cost of removing it and installation into another vehicle be covered by the receiving family. Tramanco car modifications have estimated costs of removal and installation to be between \$2000 and \$6000 (depending on type of vehicle).**

**If you are interested, please contact Inga Miles on  
Ph: 3291 5888 or email: [inga.miles@mamre.org.au](mailto:inga.miles@mamre.org.au)**

## **Date Claimer**

If you're interested in coming to the

### **Mamre Community Retreat**

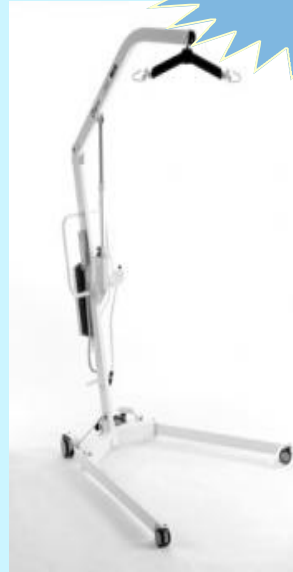
this year, it will be on from

**Friday 2nd September to  
Sunday 4th September 2011**

at Bornhoffen PCYC camp in the  
Numbinbah Valley.

Registration forms will be out  
soon!

## **Wanted to Buy**



A family is looking for a hydraulic hoist for their daughter's use in her therapy room.

If anyone has one 'collecting dust' and would like to be rid of it or are willing to let it go for cheap please contact Andre or Marian on 54330693

## **2005 Mercedes Vito Van for sale.**

Automatic, Metallic Silver. Rego June 2011. Roomy interior, current shape, with all modifications for wheelchair transport. Includes Rampboss manual flip-out external ramp and automatic retractable wheelchair anchor points. Seats 5 plus a passenger in a wheelchair. Many extras including two ceiling mounted DVD screens, chrome hub trims, mag wheels, electric windows, central locking and internal wing mirror controls, custom built centre console for storage, power steering, cruise control, independent air-conditioning front and rear, 10-stack CD player plus single CD player with storage in front passenger area, auto retractable multi media touch-screen providing fingertip control of entertainment components and satellite navigation, front and rear DVD players with individual screens, fuel injected 6 cylinder petrol engine, genuine sheepskin covers on front seats (grey), Waeco hot and cold esky wired to cigarette lighter for power, satellite navigation, all service history. Completely lined interior, dark tint on all windows, no solid window panels, drives like a luxury sedan with head turning good looks for this type of vehicle. Beautiful family car, only being sold because our son has moved out and doesn't want to know us! Only done 80,000kms. All custom modifications carried out by a professional coach builder employed by Mercedes Benz registered dealer, and completed to a high standard throughout. \$90,000 new, selling for \$55,000 very negotiable. Call Sue 0401 565 873

# The need for a national disability insurance scheme

It is hard to believe that in a democratic country as wealthy as Australia that people with a disability and their families are still left to struggle alone every day. Most Australians assume that if people are born with a disability or acquire one later in life, that some system, somewhere, will take care of them.

Nothing could be further from the truth.

People with a disability, their families and carers know only too well the daily struggle for services and support, how often the system fails to deliver essential services. They know how often desperate families are left to fill the gaps. There is also huge inequity – people receive different levels of support depending on how, when and where their disability was acquired.

And the situation will only grow worse in the future. As the population ages, the number of people with a disability will increase. At the same time, the number of unpaid carers – family members and friends – willing and able to provide support will decrease.

It is therefore time to take stock and plan for the future.

A National Disability Insurance Scheme represents a fundamental reform to the way services are funded and delivered. It is a social reform on the scale of the introduction of Medicare and compulsory superannuation – two safety nets now taken for granted by every Australian.

## ***A Fair Go for Australians with a Disability, Families and Carers***

The National People with Disabilities and Carer Council late last year released a report in 2009 called *Shut Out: The Experience of People with Disabilities and their Families in Australia*. The product of an extensive nationwide consultation process, the report highlights the everyday struggle of people with a disability, their families and carers to access basic services the rest of the community takes for granted as well as their daily battles against exclusion, discrimination and negative social attitudes.

*Shut Out* demonstrates that people with a disability, their families and carers are amongst the most disadvantaged groups in the nation. People with a disability are less likely to complete their education, less likely to be employed and more likely to be poor and dependent on income support. Many families with a member with a disability struggle daily with high rates of physical, emotional and financial stress.

People with a disability, their families and carers made it clear that they do not want to be seen as victims or recipients of welfare and charity. At the same time, there are many barriers to their full inclusion in the community and their participation in the social, eco-

nomical and cultural life of the nation. It is time to address some of these barriers.

## ***The Economic Case for Reform***

The number of people with a disability will increase significantly in the next twenty years. At the same time, the number of people willing and able to provide unpaid care will fall. Government is responsible for funding the difference between the two. The resulting increase in costs has the potential to overwhelm state treasuries. If current growth continues, the amount spent on specialist disability services alone will double in fourteen years. A National Disability Insurance Scheme will ensure governments have the ability to meet current and future needs, whatever the economic climate.

But it will also provide other important economic benefits. By focusing on early intervention and identifying those supports and services which are the most effective and efficient, the scheme will maximise potential and facilitate greater independence. By providing people with what they need, when they need it, the scheme will ensure people with a disability, their families and carers have every opportunity to reach their full potential.

Providing people with a disability with what they need, when they need it, should also reduce the pressure currently experienced by families and enable them to more fully participate in work, life and the community.

## ***What Would the Scheme Look Like?***

The scheme could be funded by all taxpayers through general revenue or through a Medicare-type levy. Funding for essential care, support, services, therapy, aids, equipment and training could then be drawn from this consistent pool of funds.

The principal beneficiaries would be those people whose disability has a significant impact on their daily life. Most importantly, the scheme would provide support no matter how that disability was acquired. People born with a disability or who acquire a disability through accident, injury or a result of a medical condition or with a mental illness would all be eligible for assistance.

Eligibility for the scheme would be transparent and based on careful assessment. The system would be person-centred and individualised, based on the choices of the person with a disability and their family. The system would focus on early intervention and providing those supports which produce the best long term outcomes. It would maximise opportunities for participation and productivity. The system would be fair, efficient and equitable.

There are difficult issues which must be confronted before the scheme can be introduced, such as eligibility



criteria and levels of benefit. The interface between the disability, aged and health care sectors must also be assessed. That is why the Productivity Commission has been given the responsibility for conducting an inquiry into a national disability long term care and support scheme.

The Commission is being aided in its work by a commissioner with specialist expertise in disability and an independent expert panel. The Commission will conduct public consultations as part of the inquiry and accept written submissions. It is very important that people with a disability, their families and carers participate in the inquiry so that it takes account of the lived experience of disability. People with a disability and their families must have input into consideration of how the scheme will operate.

### Conclusion

Disability won't happen to everyone but it could happen to anyone, anytime. All Australians deserve the peace of mind that would come with knowing that support will be there if they need it. And we all benefit from a more inclusive, more diverse community. But this scheme will not become a reality unless there is broad-based community support. Visit [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au) for more information about how you can become involved.

*Information for this article was taken with permission from the NDIS website.*

If you're wondering what you can do to promote the need for and benefits of an NDIS, here are a couple of suggestions:

1. Ask your friends, family, colleagues to sign their support at the Every Australian Counts website [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)
2. Visit or email you local MP to outline your expectation that they will support the NDIS, no matter which political party they belong to.
3. Attend an NDIS forum. Information on forums can be found at the website above.

In essence, the NDIS will change both structure and the culture from a charity-based system to a system where demonstrated need, not diagnosis, will determine what supports and funding will be made available for the individual and/or family to choose from. Now is the time to have your say about that system and you can find out more about how you can do that at [www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)



## Ten reasons why we need an NDIS

1. The support system for people with a disability, their families and carers is in crisis. If you, or someone you love, is born with a disability or acquires one later in life, you all run the risk of falling through a huge hole in Australia's safety net.
2. People with a disability and their families and carers want to participate in the social, economic, and cultural life of the nation. But there are many barriers to their full inclusion.
3. Lack of support and services means families are primarily responsible for meeting the needs of their family member with a disability. Many families are struggling with high rates of physical, emotional and financial stress.
4. The current situation is inequitable – people receive different levels of support depending on how, when and where their disability was acquired.
5. An economic crisis is looming. The number of people with a disability is increasing and the number of people willing and able to provide unpaid care is falling. This means the cost to government is expected to escalate dramatically in the future.
6. A National Disability Insurance Scheme would provide people with a disability and their families and carers with the regular care, support, therapy and equipment they need. As a Medicare-type scheme, it would provide a secure and consistent pool of funds for these services and support.
7. It would be fair, efficient and effective. It would focus on early intervention and delivering those supports which produce the best long term outcomes. It would maximise opportunities for independence, participation and productivity.
8. It would be individualised and person-centred. Support would be based on the choices of person with a disability and their family.
9. The scheme would reframe support as investment rather than charity. Timely interventions, appropriate aids and equipment, training and development would become investment in individual capacity rather than welfare. The scheme would therefore lead to more positive results for people with a disability, their families and carers as well as being fiscally responsible.
10. All Australians would benefit from this scheme because disability can affect anyone, anytime. Everyone will benefit from building a more inclusive, more diverse community.

Inspirit Update – *“To encourage, inspire and embolden families with a person with a disability”*

Hello everyone,

No doubt you all received the Inspirit brochure at the beginning of the year outlining the events scheduled for 2011. You may have noticed the magnet which was attached to the back so that it could receive pride of place on your fridge!! It has been a busy few months but it is also hard to believe that a quarter of the year is now already over!

This year we have reinstated the Mamre coffee mornings which are being held every second Tuesday morning of the month at Newmarket and every second Thursday morning of the month at Mt Gravatt. Morning tea is provided and to give a focus to these conversations, various speakers have been engaged to attend who will have something of interest to share with families. It is fine to bring your children along with you but unfortunately, there will not be any childcare provided so you might like to bring along toys to keep them busy. For catering purposes, it would be appreciated if you could phone the relevant Mamre office a couple days before to register your interest.

In March we invited people from the Relaxation Centre to discuss ways of coping with stress and to talk about the various programs that they offer.

This month, Sandi Seymour from Queensland Parents of People with a Disability will be facilitating a conversation around the different paths in life that people with disability can take – the path of inclusion vs the ‘special’ path. This should lead to an interesting discussion! (12 April at Newmarket & 14 April at Mt Gravatt)

For the May coffee mornings (Tuesday 15 at Newmarket and Thursday 17 at Mt Gravatt), staff from Commonwealth Carers will be attending to talk about what is available for families.

In February, Inspirit held an evening conversation about inclusive education with Bob Jackson who was visiting from Western Australia. This event was well attended. Another evening conversation was held in March at Mt Gravatt on the topic of Reducing Stress and introduced the



strategy of non-violent communication. Unfortunately only a few people attended this conversation but it was an interesting and interactive evening.

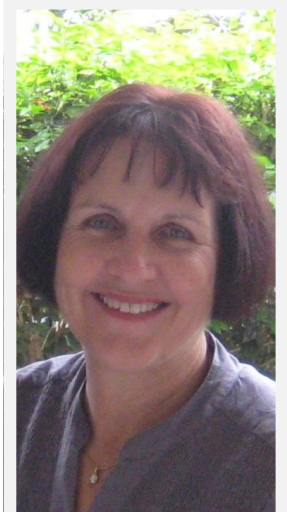
There have been some fun/relaxation events on offer too! Some of the Mamre Dad's spent the last weekend in March over at Stradbroke Island which was facilitated by Chris Gardner and Ray White. Another men's weekend away is scheduled for 4-6 November at Chris Gardner's property at Aratula, so put this in your diary.

This coming weekend a group of Mamre Mum's are heading off to Gemma Condon's home in Stanthorpe and a women's retreat is scheduled for the weekend of 22 - 24 July at the Manly Spirituality Centre.

A men's dinner was originally scheduled for Friday 29 April but because this is the beginning of a long weekend, it has been decided to postpone this until early May. Will let you know when the date and venue has been decided on.

A new direction for Inspirit this year is the introduction of two workshop series: one for families who are new or relatively new to Mamre, and the other will be for families who have sons/daughters who have recently left school or who are about to leave school and who need to think through how to develop a rich and inclusive adult life for them. Each of these workshop series consist of three sessions held on Sunday afternoons at the Newmarket office. Families will receive an invitation to these workshops and are encouraged to attend all three sessions which will focus on different aspects of planning relevant to the ages of their children. The first workshop in the New Families' Workshop Series has already been held, followed by lunch. (The inclement weather meant that the "picnic" was held inside rather than in

## MAMRE'S INSPIRIT PROGRAM



the park opposite.) The support workers employed for the morning did a wonderful job of keeping sixteen young children busy and happy!! The second of these workshops is coming up on 17th April.

The big Inspirit event for the year is Creating Meaningful Lives which is being held on the last weekend in May (Friday 27 – Sunday 29 May) at Rydges Oasis Resort at Caloundra. This is a live in workshop to give families the chance to step aside from their busy lives and spend a few days thinking through ways to create rich and inclusive lives for their family member with a disability. I know that it is sometimes hard to get away for a couple of days, especially without the children, but to have the opportunity to set aside a whole weekend for reflection, discussion and development of ideas and strategies is quite a special gift. If you are interested in attending, please talk to your Keyworker or to me about how to make it happen for you. Expressions of interest were due on 15 April but I can accept them until Tuesday 19 April. I encourage you to take the opportunity to attend this weekend which in the past, families have found inspirational and re-energising. Keep an eye out in the Mamre Monthly Newsletters for further details of upcoming events - hope to see you at some this year.

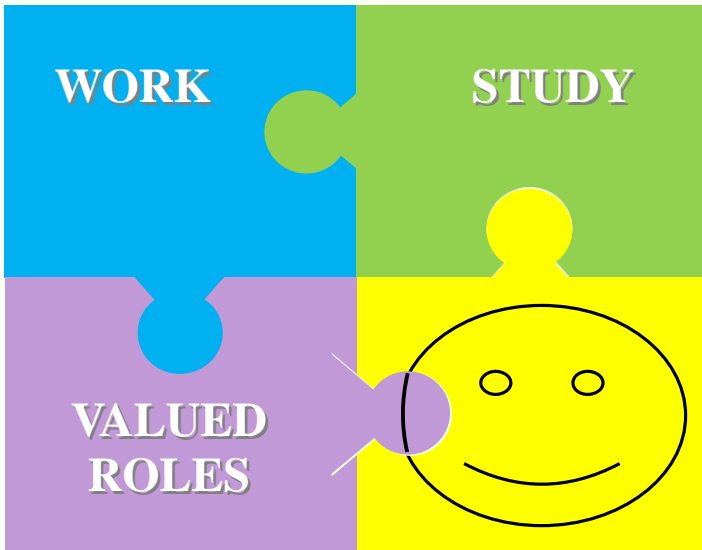
Best wishes,

Dianne Mandeville

Inspirit Development Worker

6 April, 2011

**FAMILY**



**Work, study  
and other  
valued roles.**

Where we carry out our work, studies and other valued roles are usually in places where we spend a lot of our time. In these places, we have opportunities to meet new people who may become lifelong friends or partners. These are places where we also build our skills and confidence through having a valued role. Work, study, and other valued roles bring structure and meaning to our days, and sometimes the opportunity to earn a part or full income. In the context of a good life, valued roles can be seen as one of the most important ways to develop ourselves personally, professionally and financially.

**FRIENDSHIP**

Work is something that many people with disability do undertake and depending on the individual, they have relied on either formal or informal support or a combination of both to achieve this goal.

Some people have had to be very creative about employment; the ideal job can be many jobs away, or a person may carry out a number of roles during the week. This might include: study, volunteer and paid work. Self-employment can be a lot of work to set up and maintain, but once organised, it can provide job satisfaction for some.

But valued roles are never only paid roles. While paid work might be a role that brings us more status than unpaid roles, if you ask anyone what they value most in life, the answer is usually, friendship, family, music, belonging etc. So for those for whom paid employment may not be an option there are other ways that one can contribute and gain the benefits of meaningful and valued roles. The role of artist comes to mind here. There are many gifted people who find it difficult to find paid work for their particular skills but there is still a need for artists such as painters and musicians to be present in the community. With or without pay it can prove to be a fulfilling way to contribute to one's community. Joining a group, working as a volunteer and being a good friend, son, daughter, or neighbour are also extremely valuable roles. These roles enhance a person's inclusion and recognition as a member of their community. Some people go onto higher education, and there is a lot more support for students with disabilities in the higher education sector these days. Some of this support might surprise you as it accommodates students with varying levels of disability. Students with severe mental health issues, autism spectrum disorder and physical and learning difficulties may be able to carry out studies with the particular support on offer.

For others, they may develop their own initiative such as a craft making business or a delivery service for example. High school students might like to look into a school based apprenticeship or traineeship.

Whatever path or paths you choose it may present you with some challenges. The services that exist to assist people with disabilities are never perfect and you may come across some flawed work practices. It helps to have a clear vision of what you want so that you will be in a better position to ask for what you have the right to expect of those services.

For more information and options around valued roles, you can read the Pave the Way document: Participation and contribution through work, study and other valued roles. This document can be mailed on request or downloaded from Pave the Way's website at

<http://www.pavetheway.org.au/>

[articles/2010/09/07Participation and contribution through work study and valued roles.pdf](http://www.pavetheway.org.au/articles/2010/09/07Participation_and_contribution_through_work_study_and_valued_roles.pdf)

Stephen used to come to Kedron house to stay and enjoyed mowing and whipper snipping the lawns. When the house closed the family decided that mowing might be a way for Stephen to have his own paid job. With some assistance Stephen now mows 6 properties. He is very committed to doing a “good job”.

People in community see Stephen as an asset and always thank him for the work he does. Stephen has a professional attitude towards his job. Meeting his client’s expectations regardless

of the task is very important to him and his team.



Over the last couple of years Stephen has had a positive impact on many people’s lives. A valued role like running a mowing business has given Stephen opportunities to meet new people. And it all started with a hobby! Let’s hope, as Stephen says, “the rain makes the short grass grow”.

SRV and support worker training

**M**amre believes the people we support should have the same opportunities as the rest of the community to develop valued roles and form relationships with people outside their own family.

**K**eyworkers within Mamre support the family to see possibilities for their son or daughter and to identify their son or daughters skills and abilities. This informs the support workers role and direction when supporting the person to identify opportunities in the community.

**S**ocial Role Valorization explains that developing relationships in the community is aided when the person spends time at the ‘same place, same time, same people, over time, doing the same things as other people their age, such as working during the week and socializing on the weekends at age appropriate social activities, and wearing clothes appropriate for the situation and their age. At Mamre this is done as much as possible, by culturally valued means. This is why support workers do not wear uniforms or wear service badges. Similarly, they don’t team up and support a group of people with disabilities. However, we do try and engage a peer with the same interests and skills as the people they support.

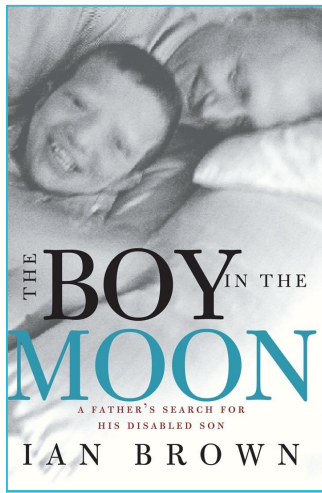
**T**he Mamre support worker training focuses on the key points of SRV and teaches support workers that the more roles a person has, the more valued those roles, the more likely the person they support is to experience a good life.

The support worker training concentrates on skill development to help the worker identify opportunities within the local and the wider community to assist the person they support to build and maintain a valued role in that community and form relationships.

Mamre also offers training to assist workers in identifying and developing natural relationships in whichever role the supported person chooses.

**U**ltimately, all the people we support have gifts and interests that can be used to assist with inclusion. The support family’s receive from Mamre is driven by the vision families hold for their son or daughter to lead a full and independent life full of possibilities.

*Sandra Cartwright*



## **THE BOY IN THE MOON** – A father's search for his disabled son

*Ian Brown*

I am not a fan of books written by parents, siblings, carers and/or friends of people with a disability. I find that they usually fall into one of two categories – the “Woe is me – aren't I a martyr??” category or “Disability is the most wonderful, awesome-est thing that has ever happened to our family!!” category. Neither is realistic – certainly not in our family – so I tend to avoid reading them to spare myself the angst.

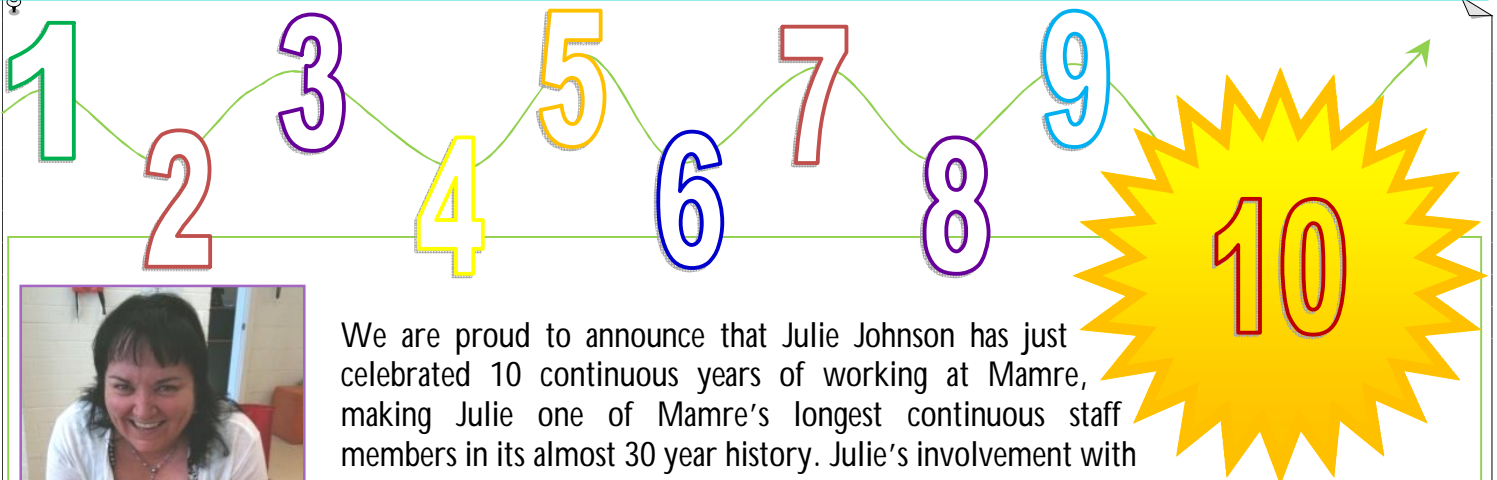
This book however kept coming up in reviews that I read; conversations I had with people and so after resisting for some time I decided to read it.

I was pleasantly surprised from page 1 as it reads like a novel – mainly due to the fact that Ian Brown (the father) was a published author before the birth of his son Walker; so I was spared the gushing descriptive feelings from the outset. Ian Brown simply and accurately writes about life with Walker, his son born with an extremely rare genetic mutation. He talks about the shock of diagnosis and what that means for him, his wife and his daughter for the rest of their lives. He talks about a life of sleep deprivation; his son's self-injurious behaviour; endless therapy sessions aimed at “fixing” the broken child; rooms full of equipment to continue the therapy exercises at home and the guilt when these are not accomplished.

I found myself gasping when I recognised myself on the page – different child; same emotions. I laughed out loud especially at one scenario when, in the hope of maintaining as normal a life as possible, Walker accompanies his parents to a dinner party. However, when left to amuse himself, Walker finds and smashes priceless crystal glasses. Ian Brown at times appears to be in awe of his son and talks almost reverently about him. At other times though he simply refers to his son as “the boy”, but his love and devotion is always evident and at times almost tangible.

From the outset, it is mentioned that the family place Walker in a group home and this is where I struggled to continue reading. I'm glad I did though. Ian Brown questions “...if Walker is so insubstantial, why does he feel so important? What is he trying to show me?” So he embarks on a “search for his disabled son” travelling the country to meet other children born with his son's condition to better understand him. He also travels to France where he meets Jean Vanier, founder of L'Arche communities and even spends time in one.

I can't say that I “enjoyed” reading this book as at times I found it very confronting, but I could not stop thinking about it for weeks. Whilst not a book that I would recommend to all it is certainly worth a look. Rose Humphries



We are proud to announce that Julie Johnson has just celebrated 10 continuous years of working at Mamre, making Julie one of Mamre's longest continuous staff members in its almost 30 year history. Julie's involvement with Mamre began in 1985 when she was one of the original community members at Carina House and 18 months later at Kedron House. In 1991 Julie left Mamre to pursue other work and study but returned in 2001 and has since taken on a number of important roles. These roles have included coordinating the Parent Support Program (now know as the Inspirit Program) and her current role as Team Leader. While Julie has contributed much to the development of Mamre's services she has filled an very important role in the life of the Mamre Community as a member of the pastoral team. Together with the pastoral team Julie has ensured the rich and ongoing life of the Mamre Community through organizing events such as the Retreat, the Christmas Carols and Picnic in the Park.

**Congratulations and thank you for your commitment Julie.**

# AWARENESS – spirituality for everyone

There is a delightful story of a group of pilgrims who met a wise spiritual Master along the road. The pilgrims asked the wise Master, 'What is spirituality?' He answered them, 'Awareness'. They waited for further comment but the Master remained silent. So the pilgrims asked him again 'Please tell us more. What is spirituality?' The Master said, "I will tell you more – awareness, awareness, awareness'. The pilgrims went on their way, talking about what the Master said. Gradually it became clearer to the pilgrims the wisdom of the Master describing spirituality as awareness. Spirituality is growing in awareness of self, awareness of others, awareness of the world, awareness of creation and above all awareness of the Divine Presence pervading all things.

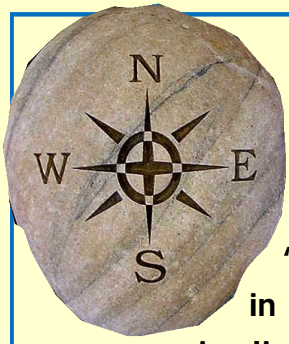
When the word 'spirituality' is mentioned probably many people would have images of holy people reading the bible, going to church, praying or at least belonging to some religious tradition. Certainly most people would be amazed to hear that spirituality is for everyone, not just for a few chosen ones. While an understanding of spirituality may embrace all those things mentioned above relating to religious practices, its meaning is much broader in scope. The word 'spirituality' is derived from the Latin word *spirare* meaning to breathe. Little wonder that all the great religious traditions all emphasise breathing in their meditation and spiritual practices. In Ta'chi, for example,



breathing comes from the centre of our being, the *Tan Tien*. In the Hebrew-Christian tradition of spirituality there is a beautiful description of spirituality as the Spirit or Divine Energy of creation (Hebrew word (*ruach*) breathing across the great void of creation and bringing all things to life (Genesis 1:2).

Research on the brain has discovered that everyone has a spiritual centre in the brain, called 'Spiritual Intelligence', enabling people to explore humanity's quest for meaning. Zohar and Marshall's book, *SQ: Spiritual Intelligence – the Ultimate Intelligence* (2000) reminds us that our DNA is wired into spirituality. Everyone has the inner capacity to seek meaning within the many complex questions of life. Sometimes we wonder about such questions as, life and death, the future of our planet, living a good life, coping with suffering, does life have meaning and so on. When faced with our friend dying of cancer we cry out, 'Why?'

There is a hunger for spirituality in our world, especially in a culture of materialism and consumerism which acts like a drug on people's consciousness. Listening to people (and our inner selves), we recognise that there is an inner restlessness, a dis-ease, which no amount of wealth will ever satisfy. We have only to look at the lives of some very rich people to realise that millions in their bank accounts do not necessarily bring peace, contentment and happiness.



Although some people would describe surfing or bush walking as 'spirituality', I will propose in this article that spirituality implies some relationship with God or a Divine Presence and not simply any activity we may do.

Spirituality may be described as:

- ♦ Making connections between self, others, earth and a Divine Presence;
- ♦ Allowing grace to touch ordinary things happening in our lives;
- ♦ Reflection and meditation to connect our outer and inner worlds;
- ♦ Taking action for justice and promoting the common good;
- ♦ Growing in love and compassion.

If a person belongs to a religious tradition, such as Christianity or Islam, then their spirituality will also be shaped by the teachings and religious practices in that tradition. For example, in a Christian tradition of spirituality, relationships with God through Jesus and the Holy Spirit would be very significant. In his teachings, Jesus summed up the quest for spirituality in his saying: *I came that they may have life and have it abundantly* (John 10:10). Living a spiritual life is to foster an 'abundance of life' within ourselves, in others by caring relationships, by involvement in the community and care for 'abundance of life' in the well being of the earth.

You will notice that one of the five features of spirituality listed above is taking action for justice. Spirituality without a commitment to justice is a hollow sham. No wonder spirituality has had bad press when we encounter so called spiritual people who are

harsh and lack compassion. In the gospels, we read (Matthew 25) that the one and only one criterion for authentic spirituality is our response to the poor and disadvantaged. In Islam, care for the poor is one of the Five Pillars of Islam. In Judaism, there is an evocative saying, 'Always pray near an open window'.

From its very beginnings the Mamre community has strong spiritual foundations. Key gospel values of inclusion, community, respect, courage and justice have been powerful influences driving the many facets of Mamre's services. Induction of new staff for Mamre emphasise how core values must be upheld and lived. After thirty years of service, Mamre can still proudly acknowledge that these core values are proactively affirmed. Habermas, a German philosopher (1986), described the intricate relationships between 'system' (bureaucracy) and 'lifeworld' (core values) in organisations. The great danger for agencies in today's corporate business climate is to drift into a 'system' way only of doing things and ignore the 'lifeworld' or core values of the organisation.

Nurturing spirituality in the Mamre community will always be an ongoing challenge and an imperative. We cannot do this alone. The Spirit of Love and Energy will always be a companion and inspiration in the quest for Mamre to base its services on a spiritual vision of life.

Kevin Treston

