
Opinions

The e-Journal of the
Disability Professionals Australasia - South Australian Chapter

Volume 1, Number 1 - March 2010

Membership of Disability Professionals Australasia – SA Chapter is open to anyone working in the disability sector –from management to hands-on support workers, from paid employees to volunteers. Disability Professionals Australasia – SA Chapter is the only group representing all workers in the disability sector in South Australia.

We are all aware that the disability sector is a broad church serving the needs and aspirations of a very diverse range of individuals. And we are also aware that there are serious concerns about the way we currently provide services and how we can improve those services to people with disabilities.

A common difficulty faced by workers in the disability field is keeping up to date with what is happening in the field across South Australia, both in practice and in policy. Another major problem has been the lack of forums for workers to express and share their views. The aim of this Journal is to provide at least one forum where workers in the field can express their views, concerns and opinions about the broad range of disability issues.

Two issues of *Opinions* will be produced each year in March and September. We invite and welcome contributions - articles, letters, book or program reviews, and general comments - from all areas of disability. And we don't mind if you 'tell it like it really is'. If we are not willing to recognise, acknowledge and discuss issues openly, we are never going to find better ways of dealing with them.

Editorial discretion applies to all contributions. The Disability Professionals Australasia – SA Chapter also states categorically that the views and opinions expressed by contributors are not necessarily those held by Disability Professionals Australasia – SA Chapter or any other individual member.

Contents

Volume 1, Number 1 – March 2010

What is <i>Disability Professionals Australasia</i> and Why an e-journal?	3
<i>Brian Matthews</i>	
What do the politicians say?	5
<i>Peter Cookson</i>	
Disability Speaks	16
<i>David Holst</i>	
A simple case of positive self presentation	18
<i>Colin Rawlings, Karen Turner, Pauline Bowman & Liz Matthews</i>	
Support: A parent's perspective	26
<i>Karen Rogers</i>	
Entrenched Negativity in the Disability Sector?	30
<i>Peter Cookson</i>	
The view from Canberra	33
<i>Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services</i>	

What is *Disability Professionals Australasia* and Why an e-journal?

Brian Matthews
Chair, SA Chapter

Background

Brian is a Senior Lecturer at Flinders University and is Head of the Disability & Community Inclusion Unit. He has a lengthy history in the Disability field, starting his work with people with disabilities in institutional environments in South Australia in the early 1970s and subsequently working in a range of community and facility based environments, mainly in South Australia. Most of his work has been as a Psychologist working with people with intellectual disabilities, autism, and their families, although he has worked in a range of disability areas and issues. Brian has been involved with a number of professional associations but joined the Developmental Educators Association (DEA) in the mid 90s, was subsequently involved in the development of the DisAbility and Rehabilitation Professionals Association in 2001, and was Chairperson of the committee for about 5 years before DPA-SA was formed. (Editor)

Disability Professionals Australasia (DPA) has come into being in response to a need for professional recognition and encouragement of people who work in a variety of capacities in disability and related human service areas. A centralised Australian based structure has been developed to accommodate not-for-profit organisations across all Australian states and territories and to allow our New Zealand colleagues to also participate. Each geographical area has developed, or is in the process of developing, a “Chapter” to represent their interests on the National body and to facilitate and coordinate professional development and related activities relevant to their needs.

Each region in Australia and New Zealand has different histories in terms of professional groups representing people working in disability. In South Australia, the Developmental Educators Association (DEA) was formed in the early 90s to represent the interests of graduates of university based disability courses. Over time, this group became the DisAbility and Rehabilitation Professionals Association (dArpa) in order to capture a wider field of representation from professionals working in the disability sector. However, it was clear that Disability Support Workers and a range of other people who work in the disability sector did not see the relevance of this association.

Subsequently, dArpa, moved to identify issues relevant to Disability Support Workers (DSWs) and plan a framework that would allow all professional interests in the disability field to be accommodated. A decision was made to ‘disincorporate’ dArpa and to become part of the National group that was being developed. This all happened at our AGM in November and so DPA-SA came into being.

A very useful summary of what DPA is about can be found at <http://www.dpaaustralasia.org/about.html> .

But, I think our goals really do identify just what the future directions for DPA are:

1. fostering excellence within the Profession;
2. raising the profile of the Profession;
3. facilitating the exchange of ideas within the Profession;
4. promoting minimum standards of professional competence within the Profession;
5. facilitating and providing peer support to Members;
6. facilitating and providing networking opportunities amongst Members; and
7. facilitating and providing professional development opportunities for Members.

With these goals in mind, it is clear that we need to provide regular communication about important disability issues to our Members. What better way to do this than through an e-journal and regular e-newsletters? These publications can provide perspectives on the lives of people with disabilities and the challenges that they and their professional and informal supports face in promoting individual's inclusion in the community. We are hoping that people with specific interests and experience will be willing to share these experiences with the broader community in order to promote discussion of important issues and a development of better understanding of a range of disability perspectives and lived experiences.

Central to these issues in relation to professionals working in the disability field are Codes of Ethics and Practice. Both the DPA Code of Ethics and the Code of Practice can be downloaded from the DPA website at the following links

<http://www.dpaustralasia.org/DPA%20Code%20of%20Ethics%20FINAL%2013JULY09.pdf>
<http://www.dpaustralasia.org/DPA%20Code%20of%20Practice%20FINAL%2013JULY09.pdf>

I want to encourage all professionals in the disability field to become a part of the movement toward raising the profile of people with disabilities in the community. Part of this involves highlighting the importance of these individuals receiving high quality services from sensitive and well trained professionals, regardless of these professionals' particular position within a service or an informal social support network. The first principle identified in the DPA code of ethics is as follows:

Principle of Person Centred Practice

As a Disability Professional I will value all people and support a person centred approach in which the needs and desires of the person form the basis of the support and services provided to them.

Let's all advocate for this, whether we are a Support Worker, Chief Executive Officer, Area Manager/Coordinator, Developmental Educator, Nurse, Physiotherapist, Occupational Therapist, Teacher, Speech Pathologist or any other "category" of staff or health professional identified in the industry.

Disability is an area of diverse interests. We need to look at the commonalities and acknowledge and respect the differences. Communication about important issues forms a vital part of this process.

So please take the opportunities available in the development of this e-journal to share your thoughts, experiences and opinions with others.

Want to become a member of DPA - SA?

Download an *Application for Membership Form* from

<http://darpa.asn.au>

Complete and return Form with payment to: PO Box 1088, Unley Business Centre, SA, 5061

What do the politicians say?

Peter Cookson

Background

With a State Election to be held on March 20, the Committee thought it would be a good idea to find out what our current politicians felt about some key issues in the disability area. A series of questions were developed and circulated.

Here are the politicians' responses.

(Editor)

Introduction

On July 29, 2009, a Forum was held for Disability Support Workers (DSWs) to discuss issues which they felt were of major concern and which affected their work. A very broad range of issues were raised. A simple survey of five questions based on the most commonly raised and most important issues to come from that Forum was developed.

On February 1, 2010, the survey was emailed to the Party spokesperson on disability issues and to all independent members currently holding seats in the Parliament. We felt these questions needed to be answered by the political parties and politicians who will again be seeking our votes in a few weeks time, especially now that we have had an opportunity to evaluate their performance on disability issues over the past four years.

We stressed that we were not seeking 'voluminous copies of party policy documents' which we know from long experience are 'rarely carried out meaningfully in the disability sector'. Rather, we asked for 'a simple, clear and informative summary of the basic philosophy and approach you or your party will take on these issues'.

Bob Such (Independent) and **Mark Parnell (Australian Greens)** returned their responses to the questions on or before the requested due date. All other members were phoned and reminded of the survey on February 19 and asked to respond by February 24.

Kris Hanna's (Independent) response was general and did not address the specific questions. His response has been included at the end of this article.

John Darley's (Independent) office phoned to say he was not responding to the questions because he is not seeking re-election this year.

No response was received from **Ann Bressington (Independent)** or her office.

The questions and the politicians' responses are reproduced below.

Question 1

Training issues were the most commonly raised issues at the forum.

The question was asked why DSW staff, many of whom have worked in the sector for a significant length of time, are now required to complete a minimum Certificate III qualification and have to

pay for themselves while also studying in their own time. Many comments were also made about the relevance of this training in meeting the needs of DSWs and the people they support.

The Office of Disability and Client Services (ODACS) report (2006) identified that budgeting for staff training is a major issue for service providers. Indeed, one agency was reported as budgeting only \$111 per staff member per annum for training. (Office of Disability and Client Services (ODACS) (2006), *SA Disability Sector Workforce Development Survey*, South Australian Government, Adelaide)

Training is such an important issue in the provision of good support, especially with the constantly increasing complexity and demands of support work.

Would your party be willing to provide additional funding targeted specifically for the provision of adequate training to all DSWs in both gaining basic qualifications and in on-going in-service programs?

Jennifer Rankine (ALP, Minister for Disability)

Sound support practices when caring for people with disabilities is a priority for this Government. We want to ensure that people with disabilities are receiving best practice and that care workers themselves are properly prepared and supported to undertake their roles.

To ensure this, the Department for Families and Communities (DFC) currently offers a range of training services.

It is a requirement that all new and existing direct support staff have or gain a minimum qualification of Certificate 3 in Disability. This is undertaken through the DFC College of Learning and Development. There are 25 enrolments per month and there is no charge for this course.

New staff attend the DFC Induction program, the Disability Dynamics Program (Foundation Program), followed [by] a further day on local worksite for orientation/induction.

The Disability Dynamics Program is a six-day program covering basic care (hygiene, showering, toileting, grooming, etc), manual handling, medication administration, principles and practices of active support and positive behaviour support. These are credited towards the Certificate 3 in Disability and Certificate 3 in Government.

Existing staff are assessed in terms of recognition of prior learning, credited with the skills they have acquired on the job, and then complete any other outstanding areas of skill/knowledge gaps through specific modules within the Certificate 3 curriculum.

As of the next College Graduation in April, around 850 staff will have achieved their Certificate 3 in Disability qualification.

DFC also has 90 staff undertaking the Certificate 4 in Frontline Management to equip them to undertake the role of Shift Supervisor.

DFC requires that organisations employ support workers who are trained to Certificate 3 where they are providing support to people with high health needs.

The sector itself has a strong commitment to training support workers and a number of large organisations such as Minda and Bedford are registered training organisations (RTOs).

NGOs are grant funded to provide a range of services, and there is an expectation that they will manage their staff training requirements within that funding.

Stephen Wade (Liberal)

The Liberal Party appreciates the need for training to support quality care.

However, consumers, carers and workers have all expressed concern about the mandating of Certificate III where it is not relevant.

A Redmond Liberal Government will review the need for mandated training and consult with service providers as to the extent to which training cannot be accommodated by current funding.

Robert Brokenshire (Family First)

Family First is looking to the South Australian community to support us in our campaign to restore vital funding for the Disability Sector.

To that end we are seeking a commitment of an additional \$110 million in recurrent funding for the disability sector from each of the major parties.

[So] YES. As part of our commitment to securing \$110 million in funding, a component of that will be to support DSWs in obtaining the training they require.

Mark Parnell (Australian Greens)

Yes. The Greens acknowledge that training is a key to providing quality support work. However, any training must be of a high quality and relevant to the actual needs of Disability Support Workers and the people they support.

The State Government has a significant role to play in ensuring that agencies are able to afford the staff time for upgrading the recognised skills-base of the sector. Also it is critical that the costs are not borne by the workers in a sector that is low-paid and facing difficulties with retention of this essential work-force. If we are serious about a quality Disability Support Workforce then Government contracts should allow for such skill upgrades and also for backfill of staff time lost in training. Additionally, contracts must prioritise quality service delivery as the primary criteria and not simply a way for the Government to get NGOs to deliver service at incredibly low costs as they scrimp and save and fundraise to make up shortfalls. The Greens will work to ensure appropriate quality control over training providers, to increase the professionalism of the sector.

David Winderlich (Independent)

Yes. If we want a professional DSW sector we must adequately fund the real costs of training.

Bob Such (Independent)

I would offer support for initiatives to consider the training needs of DSWs and the provision of necessary qualifications for all.

Question 2

The issue of how Government Departments allocate responsibilities for the provision of support services to people with mental health and disability problems was of critical concern at the forum.

People with dual disabilities (ie. both disability and mental health problems) are currently receiving poor support services. Often Government Departments 'shuffle' people with dual disabilities back and forth between disability services and mental health services with the outcome that people with dual disabilities receive no 'real' support at all.

Would your party resolve this issue and provide adequate support to all people with disabilities, including psychological disabilities and mental illness, through one Government infrastructure or procedure?

Jennifer Rankine (ALP, Minister for Disability)

The Government recognises that there is greater complexity for those with both mental illness and a disability and there are provisions in place to provide support for this particular group of people.

Many clients of Disability SA also have mental health issues. Where there is a recognised mental health diagnosis, Disability SA engages mental health services to provide specialist services for that client, with Disability SA maintaining the lead agency role.

Some people with a mental health diagnosis, who are not eligible for Disability SA services, are referred to the Exceptional Needs Unit.

The Exceptional Needs Unit provides assessment and advice for people with complex needs who may be in contact with multiple agencies, fall through gaps in service systems or are homeless and require an integrated service response.

The Social Inclusion Board headed by Monsignor David Cappo is collaborating with the sector to develop a blueprint for long-term reform of disability services right across all State Government departments.

This work will encompass the factors driving demand for disability services, across government, and will be guided by the range of reforms already being undertaken.

Stephen Wade (Liberal)

The Liberal Party recognises the need for both strong relationships and enhanced interfaces between mental health services and services to other disabilities.

However, we do not propose to structurally integrate mental health and other disability services.

With the establishment of a Community Visitor's Scheme for psychiatric disability, a Redmond Liberal Government will investigate the opportunity for such a service to also cover other forms of disability.

Robert Brokenshire (Family First)

YES. Family First supports better identification and personalisation of services for the disabled especially those with complex needs.

Mark Parnell (Australian Greens)

Yes. A 'no wrong door' approach is essential. While dual diagnosis and co-morbidity is starting to be recognised as an area where we must improve, consumers with chronic and complex needs tend to get a lot of lip service but far too often little real service. This must change. The Greens

will work to ensure that government programs address the holistic needs of a consumer and ensure that they are able to access services which address their full range of needs and not have to choose between them.

David Winderlich (Independent)

A whole of government approach is needed to resolve the false distinction between mental and physical disability. Ideally disability services should be amalgamated to give effect to this.

Bob Such (Independent)

I would agree that people suffering both disability and mental health problems should be treated within a comprehensive framework to achieve effective results.

Question 3

The issue of 'individualised funding' empowering people with disabilities to employ a wider range of people to provide their support was raised at the forum. Many people with disabilities, their families and workers in the disability sector see this as an important and fairer method of funding.

A trial of this funding model was commenced in November 2009.

Does your party support 'individualised funding' as a funding option?

Jennifer Rankine (ALP, Minister for Disability)

This Government is committed to improving choices for people with disabilities. That is why we have announced Phase 1 of Self Managed Funding in October 2009.

This approach gives people with disabilities control of funding that has been allocated for their support needs by enabling the individual to choose how, where and when they receive the support they need.

It is anticipated that the total number of participants for the First Phase of Self managed Funding will be about 50. These people are Disability SA clients who have a current allocation of funding which can be transferred into a Self Managed Funding arrangement.

The first phase of self managed funding is about learning through action and an independent evaluation will be conducted as Phase One progresses.

It is planned to extend Self Managed Funding to all those who are eligible after the first Phase is completed and evaluated.

Stephen Wade (Liberal)

In our policy released in April 2009, the Liberal Party made a strong commitment to individualised funding.

If elected we would fast-track implementation of individualised funding such that by the end of our first term of government all people with disability who wish to access it should be able to do so.

Robert Brokenshire (Family First)

YES. Family First supports individualised funding, care and support with greater autonomy (where possible) given to the care recipient in how funding is spent pertaining to them.

Mark Parnell (Australian Greens)

Yes. The Greens believe we must transfer the power from government and service providers to enable those with disabilities to determine their own best interests. This includes support for self managed funding.

The Greens welcome this model to South Australia and are committed to ensuring that it is not set up to fail. We have some concerns that the approach currently taken is potentially a half-hearted attempt rather than real reform, and that, for example, large amounts of paperwork required from consumers appears to be serving as an impediment to the success of the trial. We also understand that some people are actually worse off because of a lack of adequate choice in providers and care options, as well as Disability SA taking a 'share' of the package provided. These issues must be urgently addressed. The Greens will monitor this with great interest over coming months and continue to work for real consumer empowerment.

David Winderlich (Independent)

Yes. Funding should cater for the individual and their family rather than the specific disability.

Bob Such (Independent)

I would be interested in the outcome of the recent trial of individualised funding. If such a model, in allowing people with disabilities to engage their own support staff, offers a greater sense of confidence and self-esteem, this must be of benefit to the individual and be seen as a fairer method of providing support. Accordingly, I would endorse any proposal to that effect.

Question 4

Following several highly publicised deaths of people with disabilities caused by family members, there has been a high level of community concern about the provision of services to people with disabilities. This DSW Forum identified that many people working in support services for those families and individuals also have serious concerns about just how those services are currently provided.

There is a constantly increasing number of people with disabilities and their families in need of urgent respite and accommodation services. The question for families caring for a family member with a disability is "what will happen to their loved one if something happened to them (the unpaid carer)". If there were adequate respite and accommodation services the situation would not become urgent.

Would your party provide additional funding to address these respite and accommodation needs?

Jennifer Rankine (ALP, Minister for Disability)

Respite is a significant support for people with disabilities and those who care for them.

The Government provided \$15.3 million for respite support in 2008/09. In addition, HACC funding of about \$10.5 million has been allocated for respite services across the State in 2009-10.

Through the Disability Assistance Package, Disability SA now administers the Respite for Older Carers packages, available to identified carers in South Australia.

On 10 December 2009 an additional \$31 million in funding over the next four years was announced for disability services to give families more respite and more in-home support.

In January, Disability SA appointed two Senior Project Officers for Respite to streamline access to respite services and improve ways of utilising existing respite vacancies.

This Government understands that safe and supported accommodation is a critical issue for many families and we are on track to meet our target in South Australia's Strategic Plan to provide 1,330 supported accommodation places by the year 2014.

In June 2003, the number of group homes places in the community was 665 and by June 2009 it had reached 1,018 places.

The Government will continue to deliver a significant number of supported accommodation places across South Australia through a range of funding programs such as:

- The Disability Assistance Package with \$72.9 million over four years (matched by the Government) being targeted at new supported accommodation places, intensive in-home support, respite and individual care packages. With this funding the Government aims to provide supported accommodation for 92 people, respite places for 1,295 people, individual support packages for 650 people and 102 packages on in-home support.
- One-off capital funding of \$8.09 million for the Supported Accommodation for People with Disability with Ageing Carers program which in combination with Nation Building funding will provide accommodation for 42 people.
- The Strathmont Centre Redevelopment and Community Living Project, which has seen 135 residents move to 27 purpose-built houses. A house for a further 5 clients will be available for people to move in to in June 2010.
- The \$9.5 million Younger People in Residential Aged Care (YPIRAC) Program, which has so far seen 55 younger people with disabilities either move out of, or prevented from, entering aged care. In addition, work is underway to establish 5 new supported accommodation sites across metropolitan Adelaide.
- The Homes for 100 project is a partnership between the Government and Bedford for which the State Government has contributed \$5 million matched by \$5 million from Bedford. By the end of 2010-11, 32 homes are expected to be completed across South Australia.
- This Government is also coordinating the building of 44 new purpose-built houses funded by the Federal Labor Government's Nation Building – Economic Stimulus Plan (NESP). Building is expected to start in April. The \$22.3 million project will build 44 houses which will provide 92 places for people with a disability. In addition, 85% of houses being built under the NESP program will be disability accessible.

Stephen Wade (Liberal)

A Redmond Liberal Government has committed to an additional \$10million to disability services, including respite and accommodation services.

In addition, within a year of being elected, we will undertake a comprehensive assessment of current and future need for disability services in South Australia and a strategy to address that need.

This information base, transparency and accountability will support the case for ongoing funding allocations.

Robert Brokenshire (Family First)

YES. Family First is appalled at the lack of investment and support in respite and disabled accommodation. More information on this issue follows in our further policy information.

Mark Parnell (Australian Greens)

Yes. The Greens will work to ensure that those who need accommodation are able to access it in a timely manner. Any accommodation options must be age and/or culturally appropriate, provide independence and dignity and ensure supports where needed. The Greens know that adequate respite services are also essential and we will strongly support the provision of respite for carers.

David Winderlich (Independent)

Yes. Again we should meet the real costs of care, rather than as at present using carers to subsidise support. Funding should support carers rather than bureaucracy.

Bob Such (Independent)

I am only too aware of recent tragic deaths of people with disabilities caused by their own family members which highlight the urgent need for respite care. Carers bear a huge physical and emotional load. I would support funding to establish additional respite and accommodation where it is badly needed.

Question 5

Many of the issues raised at the Forum were related to the lack of adequate funding of disability services. In the current economic climate, we seem to be constantly reminded of the difficulties of even retaining current funding levels and have witnessed regular cancellations of expected and long overdue projects and programs.

Although Government tells us that they are constantly increasing funding levels (at a maximum level of about 5% per annum and as low as 2.5% per annum), we also know that the levels of unmet needs are rising by about 7% per annum. The overall situation for people with disabilities has been constantly deteriorating and will continue to do so.

What strategies and methods would your party implement to increase the level of funding for disability services?

Jennifer Rankine (ALP, Minister for Disability)

In 2002, the Government inherited a disability support system that was under-funded and disjointed. The Rann Government is aware of the ever-growing demand for disability support services.

This is why this Government has increased funding for disability services by 87% since 2002 when we were elected – from \$123 million to \$233 million in 2009. This has meant that 4000 more people with a disability now receive services – an increase from about 15,000 to more than 19,000 on latest data.

Since 2002, the Rann Government has spent an unprecedented \$43 million on equipment for people with disabilities (including one-off payments of \$23 million).

In 2008, a new single Equipment Program, which also provides home modifications, was established reducing waiting times for assessment and some equipment and addressing unmet need.

South Australia also provides services to a far greater proportion of our disability population than the other states – 46% of our disability compared to the national average of 32%.

The \$31 million in additional funding for disability services announced last October is already providing 284 families more respite, more therapy and more in-home support.

A Rann Labor Government will continue to seek ways to improve the delivery of services and improve choices for people with disabilities.

We are aware that people want choice – and we will ensure a range of services including different accommodation choices will continue to be available.

Our reform agenda focuses on using resources more effectively, building greater levels of equity and accountability into the disability service system, and opening the system up to new ways of providing services.

Stephen Wade (Liberal)

A Redmond Liberal Government will provide leadership, actively pursuing a Vision for disABILITY - to lead the nation as a State which supports “full and effective participation and inclusion” by people with disability. We will work with the broader South Australian community to embrace that aspiration and make it a reality.

A Redmond Liberal Government is committed to developing and implementing a plan in our first term to bring our vision to reality.

As the first steps in the first twelve months, we will:

1. ENGAGE – establish a peer visiting program where people or families with disability will be visited at an early stage by another person with disability or a parent to help them envision and pursue a decent life – for infants this will build on the home visits already provided for new parents;
2. SUPPORT – fast-track the development and implementation of individualised funding and ensure that all clients who wish to access individualised funding are able to do so by the end of our first term; and

3. PRESERVE – plan and deliver support so that no person with disability is at immediate and high risk of harm to themselves or others through a lack of support, thereby eliminating the crisis waiting list.

Within our first year of government, a Redmond Liberal Government will produce a Vision for disABILITY Plan with the following elements:

1. FACING THE CHALLENGE – produce a comprehensive assessment of the current and future prevalence of disability and of the support people with disability will need.
2. FOCUSING ON THE PERSON – put people with disability and their carers in control of decisions about their support, in particular, through individualised funding and person-centred support and planning.
3. DELIVERING MORE SERVICES – increase resources and undertake sector reform with the urgent objective to eliminate the crisis waiting list (Category 1) within the first term of a Liberal Government.

A Redmond Liberal Government will provide \$10m additional funding over four years to target the Category 1 waiting list.

4. PROMOTING QUALITY OF SERVICES – enhance the quality of services including through a new Disability Services Act which reflects the values of the UN Convention and through a strong quality assurance program with elements such as independent advocacy and information, a community visitor's scheme and a restrictive practices regime.

Robert Brokenshire (Family First)

Family First will work with the sector to campaign for the headline figure of \$110 million in recurrent funding increase in the disability sector until such time as the Government of the day provides that funding.

Mark Parnell (Australian Greens)

The Greens are dismayed that the overall situation for people with disabilities has been too easily ignored. If you're not counted then in politics you don't count. Publishing half-yearly waiting lists is a good start to increase both information and attention for disability services needs but the figures still don't tell the full story. Those 'waiting' to be on the waiting list must also be counted if we are to be serious about addressing real need. Additionally when waiting lists for unmet need are seen to be too long and arduous, many are discouraged from being on the list in the first place.

With unmet need, it is a case of 'penny wise and pound foolish' as needs escalate due to cruel delays while a consumer's circumstance often grows more complex and difficult. Carers and consumers are placed under stressors and the result is that a situation escalates both in the level of complexities, crisis and cost. Addressing needs in a timely manner will alleviate such cases and in the long run works out to be a more cost effective use of the public purse. The Greens will highlight the needs for increased funding through our media and parliamentary work and we will work across party lines to achieve this goal.

David Winderlich (Independent)

As an initial measure, advocate for indexation of funding, and move for a parliamentary enquiry into the needs of the disability sector.

Bob Such (Independent)

As an independent I am unable to outline strategies and methods to increase the funding for disability services. I can, however, offer my support for additional funding to the sector to address the rising level of unmet needs and the recruitment, retention and recognition of the staff who provide essential services to people with disabilities.

Kris Hanna (Independent)

'I am very concerned that:

- services to many people with disabilities have been cut in the last 2 years and continue to be cut.
- there is a lengthy wait for equipment even when medical experts say current equipment is damaging to the health of the person with disabilities.
- Disability SA has reassessed several of my constituents 4 or 5 times when the disability is stable. This is costly and adds to the waiting period.
- support workers need good training.
- disability agencies should do more to provide suitable accommodation and adequate services to people with disabilities. If this is done, the need for family members to have respite will decrease.
- there is a need for more balance in Housing SA to ensure that there is more housing for people with disabilities.'

DISABILITY SPEAKS

David Holst

Background

The Chair of Disability Speaks, David Holst, has become widely known as a genuine resource for information regarding the disability sector. He is regularly approached by the media for comment on disability affairs. David, whose interest in the disability sector was precipitated by being the father of a severely intellectually disabled 25-year-old daughter, is also well-known around Adelaide as the Director of Sales and Marketing for the publicly listed Adtrans Group and a former high profile SANFL league footballer. Clearly, the high level business and sporting contacts that David has been able to bring to the disability sector have provided a leveraging of power that is not often available to other smaller groups who, despite their best efforts, have failed to get recognition in the media and by the general public.

Further Information can be obtained from www.disabilityspeaks.com.au (Editor)

For an organisation that is less than 12 months old, Disability Speaks has had a significant impact on lifting the profile of the disability need in SA. By many, it is now recognised as the peak body for fair, factual and balanced advocacy comment

Established by volunteers and without any government funding, the primary aim of Disability Speaks is to build a broad network of recipients of important disability sector information. Disability Speaks believes that in the past, while the sector has raised its voice and talked often and loudly about unmet need, sector opportunities, and the need for the broader community to welcome and embrace people with disability, these voices have largely failed to have an impact outside the disability community.

In essence, whilst the disability sector talked a lot, it has largely talked to itself.

Disability Speaks has embraced modern technology, including email communication networks, websites and Facebook, and attempted to bring together under one banner a united sector group that will raise the interests of the wider community over and above the interests of any specific group within the disability community.

Too often in the past, groups within the community, often battling for survival and literally the crumbs that the government has distributed for disability services, have staged titanic struggles for prominence. This has often been to the detriment of others within the sector as so many have to fight for desperately needed individual resources.

Whilst the government may deny it, the significant divisions within the sector have enabled the idiom "divide and conquer" to be realised. There have been few positive outcomes.

Disability Speaks believes that it is critically important that the disability sector puts aside its individual needs and fights in a united fashion by communicating important messages to the powers that be, while at the same time, attempting to generate support from the wider community and critically, from the media.

In less than 12 months, Disability Speaks has established a database of both state and national links with nearly 4,000 recipients that largely includes all major SA disability groups, disability service users, and their carers and supporters. Most importantly, the database media releases have become recognised by the media, all major political parties and Disability SA executives and staff as presenting a balanced and factually accurate synopsis of disability events and occurrences.

This credibility has partly been established by building on the history of Dignity 4 Disabled which was a political party established in 2004 in SA and which contested the 2006 state election. By running 14 candidates across both Upper and Lower House seats and presenting itself in a highly professional manner, it formed a strong base for the credibility of high level, professional lobby groups in the disability sector for the future. While not surprisingly failing to win a seat at the last election, D4D managed to achieve significant outcomes that have been widely recognised as critical to furthering debate on disability services in SA. These included:

- The publishing of official SA disability unmet need waiting lists on a regular basis by the government. This data paints a factual picture of what is happening in the disability sector and has become an accepted benchmark for the disability debate.
- The state government agreed to, and held post the 2006 election, a broad-ranging community enquiry into supported accommodation. Holding five public meetings in both rural and metropolitan areas attended by over 600 people and with 127 submissions received, the government acknowledged that the services being provided by Disability SA were not meeting the demands of the consumers within the disability sector.
- This has given rise to a restructuring of Disability SA and a swing in focus by the department away from executive officers dictating government policy to more strategic plans and self-managed funding models that reflect the consumer demand of the service recipients and no longer the academic opinions of well-meaning but non-consumer focussed executives.

Disability Speaks is funded purely by donations, either in cash or kind, and the regular appearance of full page and half page ads in the local press suggest that the donations have been regularly forthcoming. Disability services are being seen more and more by the wider community as a genuine problem that is a social disgrace.

The ability of Disability Speaks, through its database and media contacts, to focus on timely and sometimes tragic occurrences like the alleged murder of a severely disabled child, has been skilfully used to raise bigger issues within the community. The embracing of these issues by the community, supported by the media, is an encouraging sign for the future.

At this stage, whilst both major parties have been paying political lip service to the acknowledged disability crisis, neither the ALP or the Liberal Party has done anything substantial to alleviate the distress and attack the fundamental issues driving the failure that people with a disability feel immersed in.

The 2010 election campaign promises by major parties are far from robust at this stage.

As such, the task for Disability Speaks is a long way from complete. Disability Speaks is being set up and structured in a manner where it is not just a 2010 pre-election lobby group but hopefully a long-term advocacy group that will sustain its professional commentary and input to the disability debate over many elections and many years to come.

A simple case of positive self presentation

Colin Rawlings, Karen Turner, Pauline Bowman & Liz Matthews

Background

At the Disability Support Worker Conference in Melbourne in November 2009, this presentation by the first three authors was widely applauded. Professor Kathy Boxall from the University of Sheffield said a few words at the end of their session and praised the presenters and 'wished they had this sort of honesty and approach in England'. Professor Mark Benner from Canada also thought this was among the most honest and convincing presentation on Support Worker roles that he had heard.

The three support workers who presented this paper have been employed by the E W TIPPING FOUNDATION NETWORK at Lakes Entrance in Victoria, Australia for only a short time. Liz Matthews is their Manager and can be contacted at Liz.Matthews@tipping.org.au (Editor)

Introduction

Hello. My name is Colin Rawlings and I work for EW Tipping in Lakes Entrance.

Our presentation today explores the myths and perceptions around the workers in the disability field and how the truth is very different.

Before I started work in the disability field my perceptions of people with a disability were based on what I saw and read - that on the whole they were helpless and hopeless; charity cases who needed "looking after".

As a member of the community, I would see people with disability but I would make no effort to communicate with them - considering that I had not the skills or patience of a "carer". I considered I would "do it wrong" and "look foolish".

I believed that "carers" took total responsibility for a person - catering for their every need (mostly bathing, feeding and medicating).

I thought it took special people, mostly women, to dedicate their lives to helping someone else - and I was not one of them - not special and not a woman!

I had heard the term "carer" used in the media - mostly around worn-out parents who were looking after a son/daughter in their own homes. They were often portrayed as exhausted and without services to help them.

When workers were asked what they did in the disability field, I heard them reply "Oh, I'm only a carer". I "look after" clients.

When I started in the job, I found it to be so much more than a caring role. It was a support role - enabling people with disability to reach their potential.

A personal view

For most of my life, I worked as a truck driver. I enjoyed my work, but felt there was something missing; I wasn't going anywhere - except to the next delivery.

I talked to a family member. She had two children - one with Asperger's and another with Tourette's Syndrome. I spent a bit of time with these children and found I could relate to them and that I enjoyed the experience. I realised that a "carer" role was not appropriate for them. They just needed support to learn, grow and enjoy their lives.

First impressions

Still carrying some pre-conceived ideas I went for my first interview.

I still thought people with disability were housed in a large building, like an institution. And there they would have their basic needs met - and that was all.

The Direct Support Worker role was explained to me and I began to move my thoughts away from the "carer" role to one of supporting a person to be as independent as they can in a normal environment. I thought this sounds interesting.

As the interview progressed, we came to a section on Personal Care. I had not considered what that meant, until it was explained to me - bathing, dressing and wiping bums (well probably not in those words exactly but that's what I heard)!! I tried to hide my reaction but inside I was saying "NO WAY!"

I went home to think ... And the rest as they say is history... here I am 2 years later and I haven't looked back or regretted my decision for one moment ...

Help me understand

When I started work, I grew to understand the role better. Personal care was just a small part of the holistic supports I would undertake in supporting a person with disability - one area they couldn't manage themselves.

There was so much more! I was supporting someone to make choices, choose goals and reach their potential. It was so much more than just being a carer!

With training and working within a positive team I learned more about communication, independence, their rights and how we played a pivotal role in ensuring opportunities for the people we support to be valued within their own community.

The more I learned, the better I could support them.

I could enhance their life experiences - support them to go places and have different experiences.

I had an important role in all this - A professional role.

Changing focus

So what can we do to foster a culture change?

For a start we can stop calling ourselves "carers" and telling people we "look after people with disability".

The word "carer" conjures up images of a motherly or fatherly type figure. It promotes the stereotypical view of a "babysitting" service.

We can take pride in the growing professionalism of the field. We can educate ourselves by gaining qualifications, networking with others professionals and educating the community by

example and through raising the bar in how we - Disability Support Workers - convey the duties, tasks, roles and responsibilities of our chosen profession in a positive light.

We can maintain our client's dignity by not taking large groups out to the shopping centre. We can provide options to promote independence by not ordering their coffee in a café. We can support people with a disability to pay for their purchases - not hold their money in a plastic money bag and pay for it. We can provide opportunities for new and different experiences.

We must ensure that we present people we support in the most positive light - being ABLE and being an INDIVIDUAL. The more the community sees people we support ACHIEVING, the more perceptions about our roles will change. They will see that we are no longer just carers but highly skilled & trained professionals who have the knowledge, experience and capacity to support people with a level of support needs to gain independence and undertake the same transitions in life we all do.

How do you perceive your role

So where do we go from here? If we continue to say "I just go in there to care for and look after people with disabilities", what does this suggest?

That the people we support can do nothing without our help! Does this message therefore promote that we as Disability Support Workers are incapable of growth and development within our own career paths. That we have not evolved from the days of institutionalism? That we just stick to a daily routine, shift after shift after shift (not easy to say). That we don't have the ability to think outside the square. That we are not responsive to the changing needs of the people we support – that we are inflexible? That their lives are boring - but not as boring as our jobs.

So why are you still here? Can't find another job?

How far away from the truth is that?

The people we support are living NORMAL (for the want of a better word) lives. They shop for food, clothing and personal items - the same as every other individual in the community.

They go out for dinner as we do. They help prepare meals, learn new skills and spend time in the community following their own interests.

And the good news is that we are out there supporting them. Tell me that it's boring. We are getting paid to support them to have enjoyment in their lives - and that makes our jobs FUN!

Terminology and our capacity to self promote

So what of the Direct Support Worker's role now?

What helps us to be the best?

Education, training, knowledge, skill development, experience, information sharing and valuing the roles we have chosen.

We are given information which enables us to support people better. We show intelligence and a willingness to develop our roles by embedding this information in our practices.

We are constantly up-dated on changes to policy and legislation so we are more informed and utilise this information on a daily basis. Consider all the policies and procedures you have within your own organisation ... think of the disability act and other legislative requirements that you have learnt, understand and implement.

We receive training on different disabilities and how to support each individual more effectively.

We are involved in Personal Plans which help focus our work on supporting people to live the lives of their choice. Think about the skills and abilities we use to develop plans – we assess, we plan, we implement, we evaluate, we source, we communicate, we acknowledge, we understand

We come along to conferences like this, where we can network, gain new ideas and practices to utilise in our services and share information. We promote within our peer groups the capacity to professionalise our work and to enhance and celebrate the role we play in supporting people with disabilities to be the best they can be

We learn through the success of the people we support

AND SO MUCH MORE

Oh no, you didn't just say that

So when we hear the words – “they depend on me to do everything”. We shudder and want to scream NO THEY DON'T!

And when workers list the duties they single-handedly perform - we ask WHY?

If your role is to do all the house-work, cook all the meals, make sure people wash properly – don't forget behind your ears - and tidy their rooms for them, then what are you doing? You are supporting people to be exactly what we don't want them to be - helpless and hopeless.

And what of you? There's a distinct smell of “burning martyr” in the air and it's not good.

The role is now to get the people we support to take an active part in their own lives. Therefore our terminology and the way we impart the career aspects of our roles to others is in positive self presentation. If you need to make a list - try swapping housework, cooking meals etc with I advocate for the rights of people with a disability, or I support people towards greater independence, or I support people through transitional periods in their lives. I communicate, I understand, I acknowledge, I promote, I implement. - And so the list goes on!

Now that's more like it

One of the greatest achievements for all of us as direct support workers is to see people we support SUCCEED. It is an honour to be part of this process.

The more they achieve - the more we achieve. But do we celebrate this? Do we congratulate our peers for a job well done?

In the past, workers and parents may have been told that the person with a disability would remain child-like forever - you know those care plans that stated --- has the intellectual capacity of a 2 year old - and will never achieve anything.

What a great feeling it is to be able to challenge that statement and see results. AND as DSWs, we have been pivotal in implementing these changes! So we need to challenge those statements about the negative aspects of the disability support worker's role.

Do we as a DSW allow some of our team to “bash the work” we do in a public forum? What do we do in a positive non-targeting way [to] try to change this perception?

Do we allow some of our team to undertake tasks that create greater dependence and reliance by the people we support - deskilling and not say anything? What about all the hard work you've put in to foster independence and decision making?

Do we think of strategies on how to eliminate this way of thinking or present these work practices in a positive light that is not detrimental to our co-workers? We come up with strategies

on a daily basis for the people we support ... yet we find it difficult to implement [changes] with our peers?

Community access? - I don't think so!

Let's just take a step back in time for a moment to something I like to call bus therapy programs.

How many of us can think of occasions where comments such as - "I just need to pop home to pick up something" or "I just need to do some personal shopping to save time on the way home so we might as well take the people we support out for community access." And it's entered into key worker reports or the communication book as an activity or outing?

How about "let's take everyone for a drive in the bus to fill in time, don't worry about putting their shoes on, we won't be getting out!"

A whirlwind tour of the area, with the people we support flattening their noses against the windows of the bus for a few hours. The view may be nice, but it's gone in a flash. It's the same view they've had for the last 55 whirlwind excursion trips made to fill in time!

And if you did manage to stop the bus and allow the people we support out, it created one of the probably most memorable perceptions in the eyes of the community - the succession line. You know, where people with a disability tag along in single file through the shopping centre - holding hands? And often it was so the DSW could look at what THEY wanted.

Trying something new – How times have changed

Thankfully Bus Therapy is outlawed in good organisations. Long may it remain so!

Disability Support Workers are now actively promoting community access by implementing individualised programs in response to the needs and choices of the people we support. While there are limited occasions that a bus journey is needed as part of the behavioural support strategy – as disability support workers we have evolved and acknowledged the possibility of other alternatives - a long walk or swim can have the same outcome and it's something that has been developed through planning.

Community access is about having a plan, working in partnership with the person you are supporting and achieving the outcomes that have been identified by the individual - whether this is joining the local library [or] gym, going to the pub or going to the movies.

It's also about duty of care – dignity of risk. As DSWs you ensure that you have provided all the support that is required for community access under "duty of care". However, you ensure the person you support has the right to make mistakes or not get something quite right the first time and to try again - "dignity of risk"

Well done you! Did you celebrate? Did you acknowledge the achievement? Do you feel empowered? Because you should - look how far you have come.

Out with the old

The old way of working with people with disability was to make ALL the choices - from what they would eat, wear, do during the day - even what they watched on TV. Of course workers had to censor programs - some things are just NOT NICE for people we care for to see. This meant for some people they were stuck in a time warp never getting past ABBA or The Sound of Music or Gardening Australia as far as their entertainment tastes were concerned – it was safe and acceptable. As DSWs we actively protected people we supported - it was easier that way.

Weekend activities were chosen by the staff. It was easier and fitted in with the staff's agenda for the weekend ... their schedule of activities. But we couldn't leave until the staff had completed all the housework - it was quicker than encouraging the people we supported to learn and develop independent living skills.

If a staff's choice of activity coincided with what a person wanted, it was pure bad luck. People were not encouraged to take part in ANYTHING.

Mini golf, fishing, surfing - much too dangerous. They wouldn't like it anyway.

How many female staff have refused to take people to the footy, because THEY didn't like it??

Oh they tried that once and didn't like it was the catch-phrase.

Oh no, he was naughty last time - we won't try that again.

People with disability were not given second chances unlike the rest of us!

THAT'S HOW WE LEARNED

Transition

What a lovely word that is - learning from the past, but moving on.

Today, thankfully, we focus on the abilities/capabilities of the people we support.

We work with them to reach their potential, to realise their goals and dreams.

We support people in a positive way, continually being alert to a breach of their rights. We are aware the environment is not always user friendly and we take steps to rectify this. It may mean lobbying for a ramp or wheelchair accessible entrances and exits.

We act as an advocate to ensure their well-being and safety.

We are more skilled at identifying personal communication and supporting a person to improve their contact in the community.

We don't get one person to write up all the SUPPORT PLANS without discussing them with the individual. We sit with people we support and their families and work with everyone to get the best outcome for the individual.

We focus on individuals, not groups, yet still acknowledge that for some of the people we support there is a need to be part of a group - just like you and I like to be part of a group at times.

We acknowledge and respect differences. We respect culture. We aim for harmony.

We actively promote life planning and person-centred practices to focus on individualised activities.

Changing culture

The Carer!

It's a hard job. But someone's gotta do it!

Someone has to look after those poor people. I feel in my own small way, I am giving something back.

They're just like kids - but bigger.

It pays the bills.

At my age and with my lack of qualifications, what else could I do?

It beats working in Macca's.

The Direct Support Worker

I love coming to work.

Sure it pays the bills – it's a fact of life that we all need an income. But it's so much more than that!

Yes, sometimes it is challenging, but working with people is always going to have its moments regardless of whether they have a disability or not, its human nature

But being part of a team working towards the same goal, I am supported to learn, develop and evolve as a disability support worker. I increase my skills, knowledge and abilities to ensure quality service outcomes for the people we support.

And you know what, most days, there are plenty of laughs, mostly at my expense I might add

But it is all good. It is fun.

It is meaningful. It makes a difference and just by having the right attitude and understanding of what my role is creates a positive environment within the workplace.

I LOVE MY JOB.

To a culture focussing on -

Learning - I am continually learning.

I am learning about the people we support - but I am also learning about myself.

Since working in the disability field, I have grown. I have learned much from the two-way relationship I have with the people we support.

I have learnt to listen. I have learnt to be patient. I have learnt not to be judgmental and to get all the facts before taking action.

I have learnt with the support of the team, to problem solve, to enable people we support to get the best possible outcome.

I have learnt that the housework can wait.

I have learnt how individuals I support communicate. I have got to know them well.

I have learnt the benefit of consulting other providers and networking to enhance community integration.

I have learnt to successfully plan, implement and evaluate individual life plans

I have learnt to laugh at myself more and not sweat the small stuff.

I have learnt that I have something of value to contribute

I have learnt that I am on a career path

I have learnt that I am a trained professional

I have learnt that it's NOT ALL ABOUT ME

Effective communication

Effective communication is essential in disability services. We learn how to communicate with the people we support on a number of different levels – therefore, we have the capacity to communicate the professionalism of our roles and why it is a career.

While the terminology we use is vitally important to raise the bar in the public's perception of the professionalism of disability support work, we have to ensure those other elements of communication are on the same page - our attitude, our tone, our body language and facial expressions just to name a few

Effective communication allows us to build strong relationships across the sector.

We have a powerful positive role to project to the community and anyone wishing to work in the disability field. And yes, we do want to encourage people to consider undertaking study and seeing disability support work as a career – a profession.

We also want to avoid our most experienced, skilled and knowledgeable staff from leaving the industry because they have become disillusioned. Through effective communication we can acknowledge and value our achievements.

Positive self presentation

As a Direct Support Worker we have a responsibility to the people we support, to ourselves and the organisation we work for as well as to the wider community.

To present the work we do in the best possible light. We are highly skilled, highly trained and highly motivated.

If we are weary of our jobs, then we should change the attitude or change the job.

We chose to make our career in providing support to people with a disability. We implement a number of strategies, plans, opportunities, programs and options for the people we support.

And herein lies the problem – Why are we not capable of implementing the same forward movement and transitional thinking in our own career paths? Why do we still allow the perception of “just a carer” to be the forerunner in the public's perceptions of our roles and within our own ranks? We forget to acknowledge and celebrate our achievements - our growth and development, our capabilities and wealth of knowledge and experience.

It is time to acknowledge that it is a professional role. It is time to stand up tall and tell it like it is. Be proud of what you do. It really is a simple case of positive self presentation. We hope that when you leave you will be enthused and driven to change the terminology, communication and perceptions of the roles and responsibilities you undertake.

We owe it to ourselves and to the people we support.

Support: A parent's perspective

Karen Rogers

Background

Karen, a mother of four, has worked in the disability field for about 20 years. She has worked as an advocate for Parent Advocacy, a manager of a supported employment service, a supervisor at Autism SA and, for two years, ran a lobbying campaign, Project 141. She currently works as a Case Manager for the Disability Information Resource Centre (DIRC) in a program assisting people who have acquired disabilities due to an accident.

But Karen is also the mother of Daniel. In this article, she describes with great honesty and openness some of the issues that she has had to face. And unfortunately, she and many other parents are still facing similar problems today.

This is Karen's story.

(Editor)

"Retarded" and "handicapped" were the words used in 1984 when the doctors finally acknowledged my 4 year old son Daniel had a problem.

Daniel was born in 1980 and was my second child. I was just 20 when I gave birth. Vanessa, my first child was fourteen months old. She was bright and progressing well and had no problems adjusting to the newest member of our family. In the early stages Daniel seemed fine. He was slightly premature but still weighed a healthy 9lb 6oz. He slept well, was breast fed and fed extremely well and didn't seem to need a lot of attention but when he was 6 months old that all changed. He stopped sleeping, screamed ALL the time and just didn't settle. He seemed almost tormented and often appeared to be in pain.

I knew that something was wrong and that led me on a path of doctors visits, referrals, more visits, therapists, and finally ending up at the then Adelaide Children's Hospital (now the Women's and Children's Hospital) where after a barrage of appointments and tests I was told Daniel was and always would be "retarded". But that journey is another story This is about the path we have travelled being parents of a person living in supported accommodation.

Initially Daniel was diagnosed with Tuberoze Sclerosis, a degenerative condition which could ultimately end his life. That diagnosis later was changed to autism, epilepsy and profound intellectual disability.

When the diagnosis was given, everyone in our world knew what was best for Daniel. Some felt he needed to be better disciplined (more smacks so he learns), my ex-husband's family felt he needed to be "with his own kind", many thought he needed a firm father figure (as our marriage ended soon after the initial diagnosis). Some of the medical profession thought institutional care would be best for Daniel and many of my friends simply disappeared off the face of the earth (although to be fair, I had probably driven them away with my constant ravings when I was trying to find a cause for Daniel's problems). The good ones hung in there are still around today.

Despite all the advice, Daniel was my son and I was going to care for him. He was not going to live away from me and I was not giving up.

As the years passed though, life became difficult. Daniel was often frustrated as his language is quite limited and he would become quite aggressive as a means of communicating his frustration. Even though you know the cause, I can tell you a bite which breaks the skin and leaves bruises lasting up to a month still hurts.

Daniel was not toilet trained and “natural artwork” was a frequent exhibit on our walls, furniture, bedding and clothing. The house smelled very bad despite all my efforts with Jasol. He would trash our furniture, breaking chairs, beds and totally destroying our lounge suites which I would purchase from the Salvos knowing they wouldn’t last long.

Daniel also had a habit of absconding, often placing himself and others in great danger. There was not a fence or a lock that was Daniel-proof earning him the nickname “Little Houdini”. The police were regularly called out to search when he did his disappearing acts and they got to know him quite well. The train track was close by and a constant cause for concern.

Vanessa was often on the receiving end of the bites, hair pulling and hits and it became embarrassing for her to bring her friends into the house. Any romantic ideas I had were quickly dashed once a potential partner met Daniel until I met Graham. When he asked me to marry him, I couldn’t work out if he was brave or stupid. But he was definitely brave and here we are, 23 years on, and he is still a very supportive parent to all of our children.

Life was tough with Daniel and I knew that I had to make some hard decisions when I became pregnant with twins. I knew the twins and Daniel would both be in danger if I didn’t make arrangements for Daniel to live away from home. The problem was that Daniel was only 12 and it was no longer seen as appropriate for children to be in care.

Foster care was suggested by the professionals but I didn’t want that for Daniel. I was his mother and I loved him with every fibre of my being - and I couldn’t cope. How was someone who didn’t love him going to look after him 24/7? Not only that, if I was to put him into the foster system I had to give up all my parental rights. I was very clear about what I wanted for Daniel. I wanted him in a safe secure environment with staff 24/7 rostered onto shifts so they knew they could go home at the end of the day. I wanted to be able to visit whenever I wanted to and take Daniel home for weekends.

I made the decision I knew I had to make but there was NOTHING available. I lobbied senior bureaucrats and politicians and finally went to the media. It was the hardest decision I have made in my entire life to give up caring for my son and then I had to expose my soul to the world. It seemed the only way to get any sort of assistance was to give up your son or daughter, take them to respite and not pick them up. But I knew I couldn’t do that.

Many criticized me for doing what I did. Many said I should never have gotten pregnant in the first place but I wouldn’t have been able to continue forever anyway. He was a very difficult kid.

I fought the fight for supported accommodation for Daniel and I won. Daniel moved into a group home which was established because three other boys of Daniel’s age were taken to respite and left. I am so thankful to those other parents who had the courage to do what I could not. I was just lucky enough to be fighting at the right time. Daniel moved just 3 weeks before the twins were born.

This began a new journey in my life. A new set of people to work with and I was at their mercy. They had care and control of my son and I often felt very insignificant and disempowered (and guilty).

Over the years since this time, there have been hundreds of people working in Daniel’s home. Some have been angels, directly from Heaven and many have come from the other place. And

then there are those who are just there for the pay and nothing else. They do what they have to do but they don't go the extra mile that the angels go.

Like schools, businesses and bureaucracies, the attitude of the staff usually reflects the attitude of the management. Like staff, we have had some great managers and some also from that other unmentionable place. As a parent who wants to maintain a very active participation in my son's life, it has been important that I get to know the staff and the managers. Sadly there have been many changes in management over the years, on one occasion seven managers in a two year period. I can't even begin to imagine how hard that must have been for staff of the service.

Over the years some managers and staff have valued my input and acknowledged and made use of my extensive knowledge of Daniel's moods, behaviours and medical history including trials of medications and different therapies. Others have wished (sometimes even out loud) that I would just go away and let them get on with the job of looking after MY son.

As I said, I maintain an active involvement in Daniel's life and I see him often. Graham and I usually bring him home for a meal and a swim on weekends. The other kids also see him regularly and when we lived in the country for a period of time, Vanessa would pick Daniel up and drive him to see us sometimes. The twins, Mark and Tim, who are almost 18 also see him. They will sometimes pick him up on the weekends and bring him home for a visit. They have visited unannounced but that has caused some concerns for staff. I have tried to encourage them to be respectful of staff and other people living in the house. Daniel knows us all and he knows that when we come to the house where he lives it means he will be going out. If any of us try to talk to staff for too long he will hold our hands and drag us to the door or if we are standing in the doorway, he will simply go and sit in the car and search the console or glove box for any uneaten leftovers or lollies. I think we are important in Daniel's life – but so is food and if it's not locked up or nailed down – it's gone!

We have seen abuse in accommodation settings over the years. Abuse comes in all forms – physical, emotional, sexual, neglect - and all have happened in supported accommodation settings and institutions. Not necessarily in Daniel's house but all over the sector.

One situation that did occur in Daniel's house was that of a staff member making Daniel wash the floors in the middle of the night because he was singing. If he sang, the staff member would make Daniel get up and wash the floors and if he sang again when he went back to bed, he would have to wash them all over again. The staff member bragged about it – TO ME! Bad move! I lodged several complaints but no action was taken. The manager's thoughts were that if Daniel was singing, he might be disturbing others. Then on one occasion Daniel and his house mates had to move to another residence as work was being done on their house. I walked in on Sunday to pick Daniel up and the staff member looked at me with a big smirk and said "Big floors here". I took the matter further and despite receiving threats from that staff member, I did not let it drop. He no longer has any contact with Daniel.

I have often said to other parents over the years, getting accommodation for your son or daughter isn't the end of your problems, it's the beginning of a new lot. You just have more energy to deal with them.

On the other side of the coin though, there are people who go out of their way to make you feel welcome when you come to the house. You can tell by Daniel's interactions with them that he likes them and feels comfortable around them. The problem is that these people often don't stay. The pay is lousy and the job is often thankless. The politics in the system can be ugly and gossip is rife.

Daniel always comes home to us for Christmas Day and the last two years he has brought presents for us too. Obviously staff have purchased the presents but I'm sure Daniel likes to be able to give us something too.

Although his expressive language is limited, he can echo what other people say to him and he is tone perfect. If they have an accent he picks that up too so you can always tell who has said what to him when he is having his little echolalic chats to himself.

Recently I was asked to speak at a support worker course about my expectations of support workers. Graham and I discussed this and this is what we came up with. Some things are obvious like the need to respect people with disabilities and treat them with kindness. They have a need for good food, appropriate clothing and access to the community, their families and friends. They need something to do. Basically, they need the same as what we all need. Sometimes they just need a little more help to get it.

From our perspective, to be a good Support Worker you need to CHILL;

Communicate

Honestly

Involve (family and friends)

Listen

Learn

As Daniel's mother I have invaluable information about his likes and dislikes, what's been tried in the past and what has or hasn't worked.

Example; one of the things that Daniel does not like is being asked 'What's the matter?'

Sometimes he can seem very sad and even cry and the natural instinct is to inquire about what is making him sad. No-one knows why but this really upsets Daniel. If you ask him that question he will scream, say it back and hit or sometimes even bite. When a new worker starts with Daniel, I always ensure they know this. It is important for their own protection and for Daniel's reputation because every time he hits out or bites it's another black mark against his name.

Family can be a support worker's greatest ally. They will fight for improvements in the workplace because it is their family member's home.

Entrenched negativity in the disability sector?

Peter Cookson

Background

Peter has been involved in disability issues all his life having had twin brothers with intellectual disability. He has also worked for almost forty years in a variety of disability areas including special education, as a 'job coach' and in accommodation support services.

He is currently studying at Flinders University for a PhD degree. The topic of his research is 'Why would you want to be a Disability Support Worker?' and is an attempt to identify factors that help to make good support workers and keep them working in the field. (Editor)

In the research literature on families with children with disabilities, there seems to be a sense of negativity. Helff and Glidden (1998) surveyed twenty peer reviewed papers from each of the periods 1971-75, 1983 and 1993 and found that there seemed to be a failure to seek or report positive perceptions in the majority of papers. They argue that this negative focus may unduly influence 'practitioners ... to expect these [negative] results [and] view them as inevitable' (p. 461). Hastings and Taunt (2002) questioned the accepted belief that having a child with a disability *must* be a stressor on families. They argue that many families report positive perceptions of their child with a disability and that these children may provide positive benefits to the family. A British study on intellectual disability nursing found that a principal reason for trainee nurses' decisions to transfer to other areas of nursing was the 'negative talk' by tutors and practitioners about the work. One tutor was quoted as advising that mental health nursing was a '*more useful branch* [of nursing]' (Owen & Standen, 2007, p. 265). Perhaps this negativity has spilled over to support workers as well.

For thirty years we have been told in the research literature that the Disability Support Worker (DSW) is an important factor in the success of programs for people with disability.

- DSWs are 'crucial ... [in] determining [that] success' (Bersani & Heifitz, 1985, p. 209).
- DSWs are 'crucial determinants ... of the quality of life of [people with disabilities]' (Ford & Honnor, 2000, p. 344).
- 'Direct care staff are arguably the most valuable resource of any agency supporting people with a ... disability' (McVilly, 1997, p. 18).
- 'The most carefully conceived residential program applied in the most state-of-the-art architectural structure rests in the hands of direct-care workers' (Rice & Rosen, 1991, p. iii).

And so I could go on. Let's be honest, if the agency office were to burn down it would have less impact on the lives and behaviour of most of the people we support than the failure of a trusted support worker to arrive on time for a regular activity!

For thirty years those of us who have worked in the disability sector have been told in the research literature that the major issue facing disability agencies is the problem of recruiting and retaining DSWs. And we have also been told repeatedly over those thirty years that three main issues leading to DSWs leaving the sector are poor pay and conditions, lack of adequate training and dissatisfaction with the supervision and management of their work. (eg Larson & Hewitt, 2005; McCord, 1981). Yet public policy in the disability sector seems to have done little, if anything, to address those issues.

Discussions with senior managers of a major Government disability organisation to seek funding for research seemed to confirm my fears of an entrenched negative view of DSWs within the disability sector. During these discussions, one senior manager stated that many DSWs, at least in government employ, present a major threat to the well-being of the people with disability they support. Indeed, many of the long-term DSWs should never have been employed in the first place and would be fired if only it was possible to replace them. In regards to a survey questionnaire, it was stated that we couldn't expect a reasonable response rate because this group of employees, the DSWs, is the worst group of all in responding and returning even required departmental forms - so many of them are illiterate or have English only as a second language. And anyway, she said, the questionnaire would be too complex for many DSWs to understand and complete.

Yes, DSWs may have many faults. But it is difficult to see how such a work culture could have developed without management being aware of these issues. It is management who appointed these workers. It is management who guided the initial orientation of these workers. It is management who has supervised these workers. It is management who allowed these practices to develop. It is management who have failed to provide adequate training (eg Dempsey & Arthur, 2002; Larson & Hewitt, 2005). One Agency in South Australia budgets only \$111 per staff member per year for the training of their DSW staff (ODACS, 2006). Does management really believe, as the research literature has suggested, that DSWs would not be able to properly understand behaviour management techniques even if the training was provided (Grey et al, 2007)? Surely this poor work culture is not only the fault of DSWs but is also an indictment of the lack of appropriate management of disability support and its workers?

Management has been told for almost thirty years that the recruitment and retention of support staff in the disability sector will *always* be a problem (Felce et al, 1993). In order to stabilise the disability workforce, agencies have been advised to employ older women whose children are either at school or have left home (Felce et al, 1993) and who have difficulty in competing for alternative employment (Lakin, 1988). Surely the acceptance of these views suggests a prevailing and entrenched view by management in the disability sector that the problems of support staff recruitment, training and retention are too difficult to deal with or that DSWs are not worth the effort. And if this is the way we think about and '*support*' the workers without disabilities in the sector, what do we really think about the people with disabilities they support? Perhaps our beliefs simply become self-fulfilling prophecies.

I accept that, currently we are facing a wide range of skill shortages in many employment areas - from scientists and nurses to plumbers and electricians. With the changing population demographics and the expected increases in the number of people with disabilities needing support, surely it is even more important that we find ways of addressing the thirty-year problem of disability support. If the disability sector can not compete with other areas to attract sufficient quality staff, then we must expect serious reductions in our current services to people with disabilities. Do we really want to return to institutional systems or group and cluster homes with regularly more than twenty residents?

It is of critical importance that the disability sector undertakes research and develops management procedures and models which will explore and implement strategies to recruit, retain and train DSWs and make disability support a more attractive employment option.

References:

- Bersani H.A. & Heifetz L.J. (1985), Perceived stress and satisfaction of direct-care staff members in community residences for mentally retarded adults, *American Journal of Mental Deficiency* 90 (3), 289 – 295.
- Dempsey I. & Arthur M. (2002), Support staff in a sample of Australian community-based services for people with a disability: career intentions, personal characteristics and professional development needs, *Journal of Intellectual & Developmental Disability* 27 (3), 201 – 214.
- Felce D., Lowe K. & Beswick J. (1993), Staff turnover in ordinary housing services for people with severe or profound mental handicaps, *Journal of Intellectual Disability Research* 37, 143 – 152.
- Ford J. & Honnor J. (2000), Job satisfaction of community residential staff serving individuals with severe intellectual disabilities, *Journal of Intellectual & Developmental Disability* 25 (4), 343 – 362.
- Grey I.M., Hastings R.P. & McClean B. (2007), Staff Training and Challenging Behaviour, *Journal of Applied Research in Intellectual Disabilities*, 20 (1), 1 – 5
- Hastings R.P. & Taunt H.M. (2002), Positive Perceptions in Families of Children With Developmental Disabilities, *American Journal on Mental Retardation* 107 (2) 116 – 127.
- Helff C.M. & Glidden L. M. (1998), More Positive or Less Negative? Trends in Research on Adjustment of Families Rearing Children With Developmental Disabilities, *Mental Retardation* 36 (6) 457 – 464.
- Lakin K. C. (1988), Strategies for Promoting the Stability of Direct Care Staff in Janicki M., Krauss M. & Seltzer M. (Eds) *Community Residences for Persons with Developmental Disabilities: Here to Stay*, Paul H Brookes, Baltimore MD, 231 – 238.
- Larson S. & Hewitt A. (2005), *Staff Recruitment, Retention, & Training Strategies for Community Human Services Organizations*, Paul H Brookes, Baltimore.
- McCord W.T. (1981), 'Community Residences: The Staffing', in Wortis J. (Ed) *Mental Retardation and Developmental Disabilities*, Brunner/Mazel, NY, 111 – 128
- McVilly K. (1997), 'Residential Staff: How They View Their Training and Professional Support', *British Journal of Learning Disabilities* 25, 18 – 25
- ODACS (Office of Disability and Client Services) (2006), *SA Disability Sector Workforce Development Survey*, South Australian Government, Adelaide
- Owen S. & Standen P. (2007), Attracting and retaining learning disability nurses, *British Journal of Learning Disabilities* 35, 261 – 268
- Rice D.M. & Rosen M. (1991), Direct-Care Staff: A Neglected Priority, *Mental Retardation* 29 (4), iii - iv

The view from Canberra

Bill Shorten, Parliamentary Secretary for Disabilities and Children's Services

Background

This is an extract from the opening speech by Bill Shorten to the Australian Society for the Study of Intellectual Disability (ASSID) Disability Support Workers Conference, University of Melbourne, Victoria, on Wednesday 18th November 2009. (Editor)

To work every day with somebody with a physical or an intellectual impairment takes more than courage and reserves of patience. It takes more than good intentions, and a generalised understanding that inequality in any workplace, in any village or any community of souls, is a bad thing. It takes a kind of creative sympathy, an empathetic focus, that one finds in the army in wartime, the comrade you must fight alongside, the big battles you need to win.

No-one here will call this easy. No-one here will say their first day at work went swimmingly. No one here has not felt helpless at times, felt that they reached the point where there was nothing more they could do. No one here has not felt the frustration and anger that comes with fighting the good fight but feeling you are fighting in vain.

But it's part of what we mean by a civilisation, by a fair-go society, that such creative partnerships between those with an impairment and their carers, the disabled and their workplace comrades and managers, are attempted. Forty years ago the majority of people with an intellectual disability were either shut away in institutions or cared for, often in secret and in shame, by their families.

The opportunities for carers to improve the lives of their charges, to work one-on-one the way that carers do now did not exist. The work that you do is not simple supervision or guardianship, but an effort to connect with a person whose abilities are different to your own and to lift them out of themselves and beyond their impairment. To be done well this work requires emotional involvement. It cannot be mechanised or outsourced. It needs a genuine human connection.

I think it is fair to say that in this society we generally reward people whose jobs require physical or intellectual skills. What we do not do well is reward people whose job requires similar emotional skills and involvement. Too often we fall back on the cliché that caring professions are a "vocation", and that somehow absolves us from paying you properly.

Julia Gillard has announced that the Government will support the Australian Services Union in pushing a major test case on pay equity for community sector employees under the new Fair Work system. Under the new Fair Work system, social and community services sector workers - working in the youth, welfare and community sectors - will become covered by the Fair Work Act and a single modern award, rather than the multitude of state and federal laws, awards and instruments that currently apply.

The ASU has advised the Government that it will apply to Fair Work Australia in the near future seeking orders for similar pay increases based on pay equity grounds for social and community sector workers in the other States. The Rudd Government will work with the ASU to support this claim and provide research to back it up. I hope that this move will lead to an increase in the pay for people in the disability sector and some overdue recognition of the vital, but too often invisible work that you do.

There are over 580,000 Australians with an intellectual disability. 435,000 are under the age of 65, a higher proportion than most other disabilities. Over 300,000 have a limitation in the core areas of daily living, often in their ability to communicate. Like many people with disability, people with an intellectual disability are shut out of the workforce. These people are trapped in an internal exile within their own country.

The labour force participation rate for those aged in their 20s is around 60%. For those aged in their 30s it drops to between 34% and 46%, well below the 85% participation by young adults without disability. People with an intellectual disability tend to drop out of the work force at ages 30–34 years and onwards. Usually they do not return. And the chief culprit for this is discrimination and prejudice that still exists in workplaces across Australia.

Excellent work is done by Australian Disability Enterprises in finding fulfilling work for people with disability, in particular an intellectual disability. Recently a group of the nation's major employers, including ANZ, Woolworths and Coles signed a statement of intent recognising the need to employ more people with disability, and the benefits this would bring.

These are all good steps. However employment rates are still too low, and too many people with an intellectual disability are condemned to a life of boredom on the fringes of our society.

The most shameful evidence of our failed responsibility to people with an intellectual disability, is their staggeringly high rate of imprisonment. Research by Susan Hayes of the University of Sydney found that 20 percent of people in the prisons of New South Wales, some 1800 prisoners, had an IQ below 70. These figures indicate an over-representation of people with intellectual disability in the prison system; they compare with 1 to 2 per cent of the general population. There is little data on this issue available from other states, and no systematic attempt has been made to find out why so many people with an intellectual disability end up in prisons.

I do not believe people with an intellectual disability are genetically predisposed to crime. I do not think it is right, that in a rich country like Australia prison has become the institution of last resort for such vulnerable people. As long as this over-representation continues we know that the right supports for people with intellectual disability and their families are not in place.

There is constant and legitimate outrage and frustration about the disproportionate number of indigenous Australians in our criminal justice system. All I ask is where is the comparable outrage about the number of people with an intellectual disability in our criminal justice system?

We have done a lot of good things in disability since we came to Government. We've ratified the United Nations Convention on the Rights of Persons with Disabilities as well as acceded to the Optional Protocol to the Convention. In collaboration with the States we developed and from January 1, implemented the National Disability Agreement (NDA), which will add \$5 billion over five years for specialist disability services.

Work has commenced on the provision of around 150 additional supported accommodation places for people with disability, nearly half the total number of places expected to be achieved by June 2012. More than 6,200 respite places have been achieved, well above the target of 3,400 places. More than 770 young people with disability have been assisted through suitable and appropriate accommodation. We have increased Carers Allowances and the Disability Support Pension.

But as all of you would know, this is not enough to fix the structural flaws in the system. Demand for disability services will grow by 6-7 per cent or more each year until 2020, putting more strain on our current arrangements.

In too many cases we are dealing with a crisis-driven, patchwork of systems which are simply not enough to meet demand. A child born with an illness can receive medical and hospital treatment under Medicare, if necessary for the rest of its life. A person injured in a car accident is paid compensation under third-party insurance schemes. An employee hurt at work is eligible for workers compensation.

But for people who are deaf, blind, autistic, have cerebral palsy, Down syndrome, severe intellectual or many other kinds of disability, there is no system and no safety net. Services are rationed according to budgets, not to the growing need.

Increasingly people with disabilities are outliving their parents or eking out their youth in single-parent households, factors that are shifting the burden to governments, and rightly so.

The concept of some kind of disability insurance scheme is developing momentum. I know it has the support of many in the disability community who feel the current system is barely coping with current demand, let alone the increasing numbers of the next ten years. The Rudd Government is looking at the implications of such a scheme, but there is still much to be done before we can even consider it.

What we need to do is shift the public debate. We need to see how we treat disability as both an economic issue and a moral one.

A better system that intervenes early, that offers support before a problem becomes a crisis, and that gets people into work, and productive and stimulating work, will save us a lot of money. It will also lead to better and happier lives for people with a disability. As a society we need to recognise that it is inevitable that profound and serious disabilities will strike many of us, whether through birth, accident, disease or old age.

The work you do, the small miracles you achieve every day, the dignity your efforts give to people who are often treated as 2nd class citizens, all require a complementary effort from governments.

The writer E.M. Forster used to have the motto "Only connect". It is a motto that defines good people in any walk of life. The ability to cast one's own worries off and focus, clearly and shrewdly, on the challenges facing a person who cannot move too well, or talk too clearly, or think as fast. It is the ability you have to overcome prejudice and see the humanity of the people you work with and work for.

It is the last prejudice that we as a society must overcome, the feeling that someone who does not look entirely like a family member should be avoided, or put out of sight, or talked to as one talks to a child. This denial of the humanity of one who is suffering, does huge damage to the lives of people with impairments, often causing more heartache and isolation than the impairment itself.

But it is a prejudice that can be overcome, like learning to swim, or balance on a bicycle, or change gears in a car while learning to drive. It can be done. And it is a measure of our worth as human beings and as a civilised society that we attempt it, that we walk over and put out our hand and introduce ourselves and provide a seat at the table for all the people of Australia regardless of their impairment.

The work you do, and the work this conference is doing does make a difference and moves us closer to an Australia where these prejudices, like the institutionalisation of the 50s and 60s, is a thing of history.