

for and by people with disability

starecase

Issue 4 • January, 2014

BETWEEN JOBS

THE LAST WORD ON
EMPLOYMENT AND DISABILITY

BROTHERHOOD OF THE WORDLESS

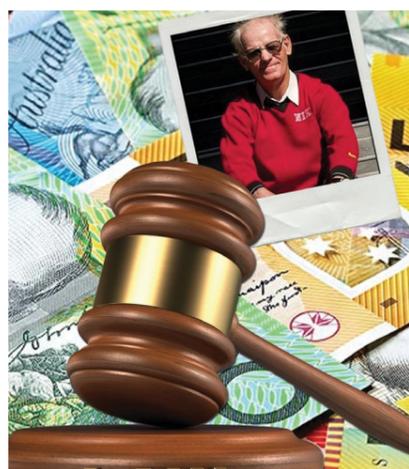
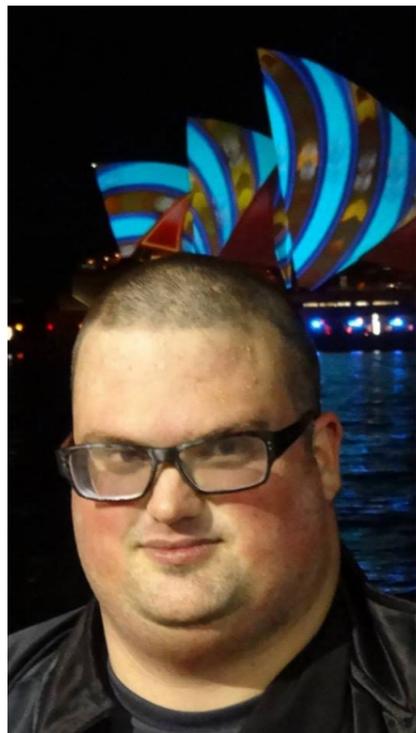
THE POWERFUL VOICES OF
THE SILENT MINORITY

- The right to work - and be paid fairly
- News on the BSWAT
- Laser Beak Man

*Don't be afraid to show your
true colours
Be Bold! Be Brave! Be Brilliant!*



THE AUSTRALIAN MAGAZINE FOR AND BY PEOPLE WITH DISABILITY



FROM THE GREEN CHAIR

Sometimes, in the disability sector, it feels like nobody is listening.

That's the experience of many people with disability who battle systems every day.

There are many voices that contribute to the disability rights movement. Parents and families, who often have a very loud voice. They've been fighting for the rights of their children for a long time, and they're usually vocal.

Disabled advocates and activists, almost as loud. We cajole and coerce and coax until our voices are hoarse.

But the voices who need to be heard the most are often the smallest voices. The voices of the 'wordless' - the silent minority, the unrepresented, and those who do not communicate by speech.

We wanted this edition to strongly include those voices - and we are overwhelmed and awestruck by the power of your contributions. Thank you.

- Pretzel

CAN YOU HEAR ME?

We all have thoughts that deserve to be spoken. Mine scream loudly in my mind but they don't make much of a commotion out loud.

I want to tell the entire world but can they hear me???

Where are all the whisperers?

Do they hear me?

Can you hear me?!

See me for who I really am, let me whisper it in your ear.

Can you hear me? - Adrian Kooistra

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A bunch of people with disability

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A bunch of people with disability

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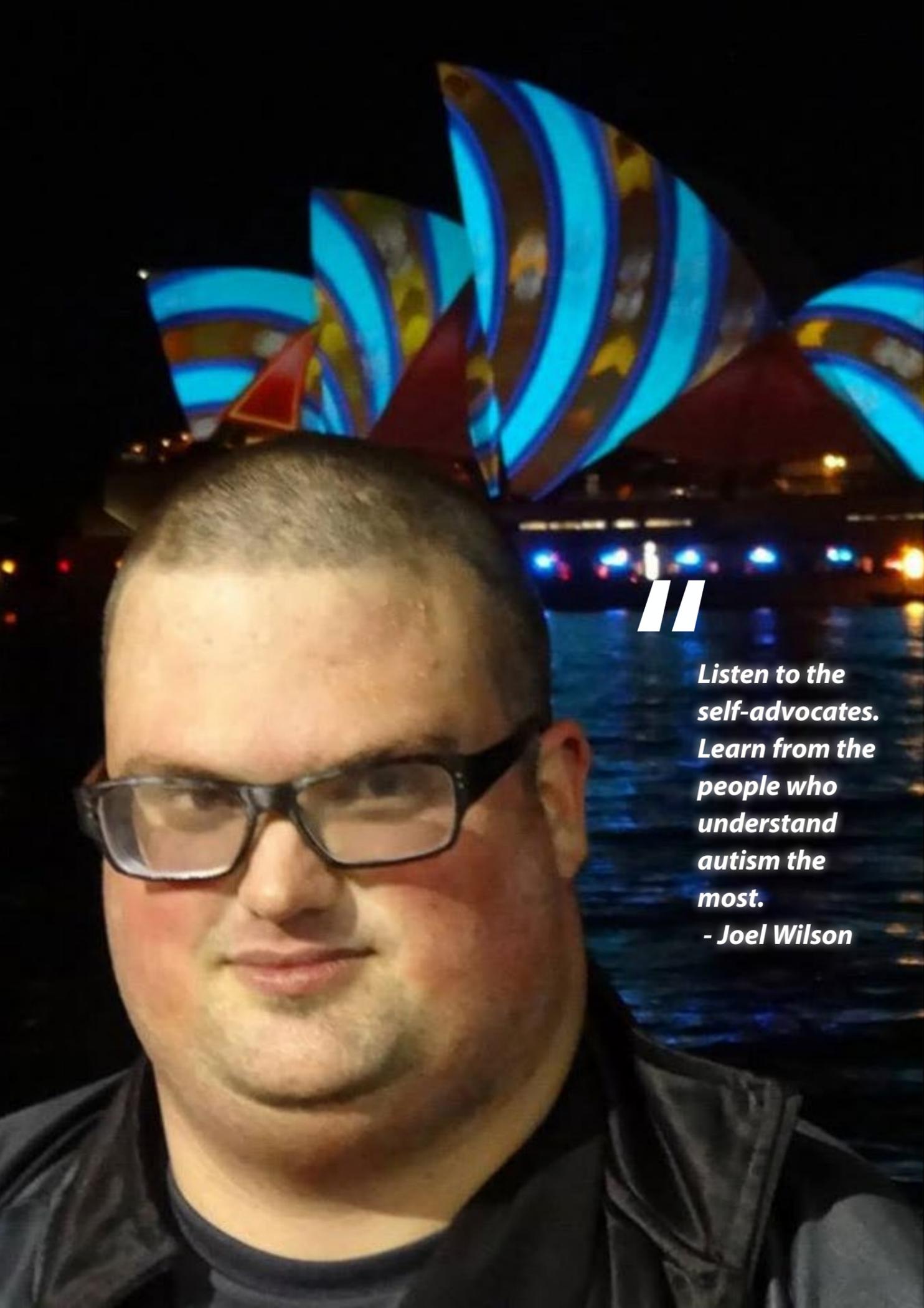
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To apply for any of the above positions, write to starecasenews@gmail.com



Listen to the self-advocates. Learn from the people who understand autism the most.

- Joel Wilson

NOT JUST ANOTHER STATISTIC

I was diagnosed as having Aspergers when I was 14. I'm 27 now. Aspergers is 'high functioning autism'. What does that mean? I learn more answers to that question every day. From social anxiety, to sensory issues which cause breakdowns; it varies on a daily basis.

People ask me what life was like before I was diagnosed, and I can never really answer that. I have next to no memories from my childhood, apart from being misdiagnosed with ADHD, which ended up in me being prescribed ridiculous amounts of dexamphetamines, but that's another story in itself. Even after I was diagnosed, not much changed. At 16 I ended up in a group home, and moved around a bit, until I settled at

the home of a former carer, who I've lived with for the last seven years.

And then there was employment.

My worst experience with a disability employment agency... I was living in a Group Home at the time. I'd been 'trailing' at a restaurant on the 4th floor of Perth's biggest department store, leaving home well before 5am to get the first train into the city to start making scones at 6:30am. I'd finish about 3pm, with an hour break in the middle. The staff there were great, and I was offered a traineeship - unfortunately, that fell through due to the lack of belief I could do it (from the employment agency's perspective.) I did that "trial" for six months - on my last day, the staff all got together and gave me a card with a

JOEL WILSON

TALKS TO US ABOUT

ASPERGERS

AND EMPLOYMENT

Joel Wilson is an autism advocate, mentor and youth leader from WA. You can find out more about him - and advocacy - at his blog, <http://www.advocacy-anywhere.com>

wad of cash that came to \$245, I remember that sum as it was the only acknowledgement of the time I was there.

Another employment experience was being placed in a sheltered workshop. We would put the velcro stickers on the SKG Radiology envelopes, and got paid about \$3 an hour for it. Yes, these work environments still exist today. I'm all for group work environments if it meets a persons needs, and they are paid a respectable wage like non-disabled people. Unfortunately that doesn't happen.

The hardest part for me with employment, having Asperger's, is the ability to focus on one task for a long time. My best job was when I was working at Dewson's in Mosman Park. It was the first time I felt accepted in a work environment. I'd travel from the group home in Bayswater, by getting a bus for an hour and a half each way. Location wasn't the greatest, but I got an age-appropriate wage, scored free cricket merch and AFL tickets from the Masters Milk Rep, got invited to staff parties, and had an awesome manager to work under. I'd stock/code check the fridge/freezers. I did that for two years, before I moved to York. When I moved to York, I continued in a similar position at the local IGA, I had more flexibility if I couldn't function properly to work, but due to concentration issues, I ended up finishing after three on and off years.

I've always struggled. I haven't worked in four years, due to a combination of finding a suitable workplace and also an ongoing foot issue. I'd like to work as a mentor with young teens and adults with autism and intellectual disabilities, to help them with independent tasks like catching the train, shopping, going to movies, buying a family member a present, etc. Not being able to drive due to poor eyesight doesn't help.

Managing Aspergers is something I'm getting better at. I'm so much different now than I was even this time last year. So more aware of the world around me, a higher understanding of who I am, and what I want to



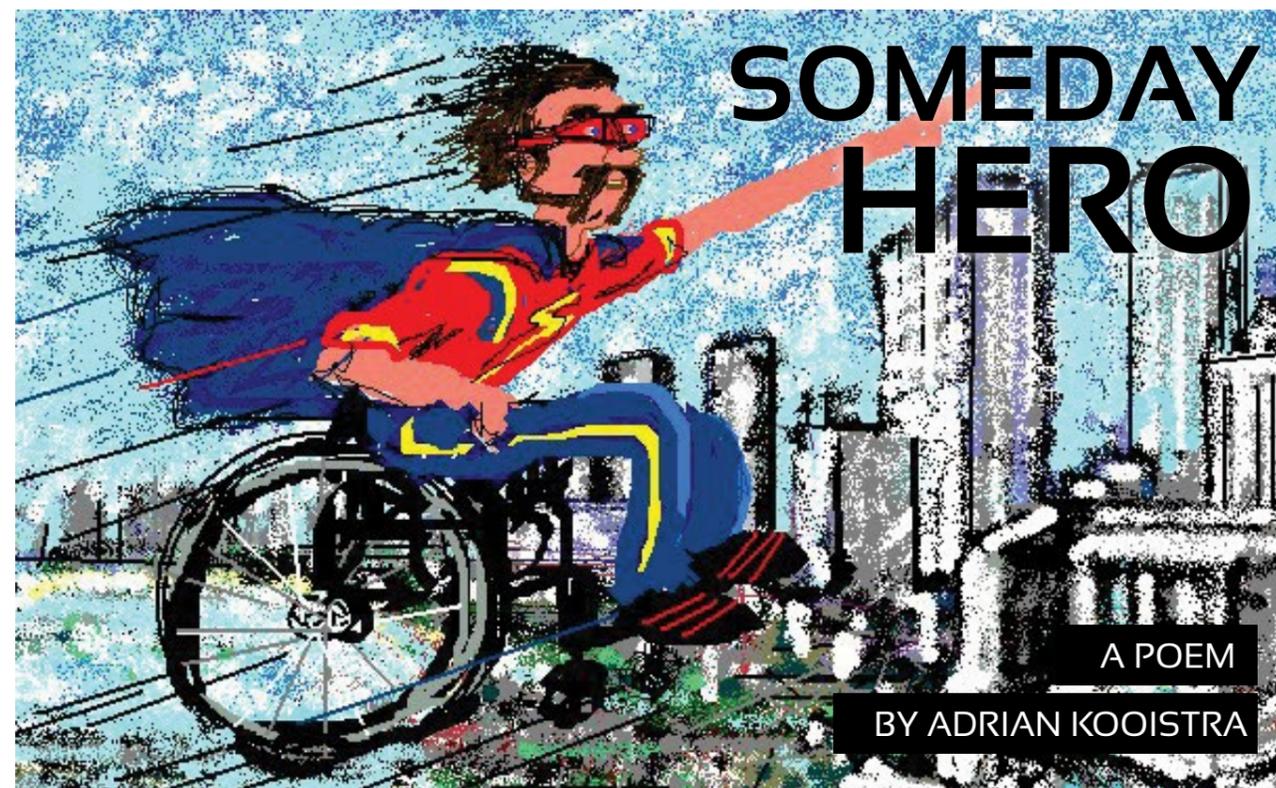
achieve in this lifetime.

Through different group homes, support and employment services, and the like over the last 10 years, I've seen so many bad things, experienced bad support. And been abused for standing up for what I feel is the human right to speak when things around you need to change. Trying to make people understand that just because I have an autism spectrum disorder, doesn't mean I am incapable of understanding rights, and that I'm unable to stand up for myself. I've seen so many people less capable than I am, being neglected and abused by the services that are meant to be taking care of them.

I'm on the Autistic Self Advocacy Network of Australia and New Zealand committee, and I have just set up my own website, Advocacy Anywhere.

So many times I hear parents that when they find out that their child is diagnosed with an ASD cry that the world is over. It's never over. My biggest advice to parents is to love their children for who they are, autism aside. Focus on strengths, not weaknesses. Live life day by day.

If there's one thing I want the world to know, it is this. Listen to the self-advocates. Learn from the people who understand autism the most.



Being friends is boring...
but being a hero is boring too
when you are trapped in a needless chair.
My heart says "run...fight... hug...kiss."
but my body says "no"
I can only dream of being her friend...
her hero....

her soulmate.
She never saw me except as a child to adore.
That will have to be enough for now.
Some day she will call me "friend"
Some day I will show her I am a hero
some day she will say "soulmate"
and she will be mine.

Writer Adrian Kooistra spent the first 22 years of his life 'in darkness', and without his voice being heard. He has been using facilitated communication for six years.
Artwork by Paul McCoy

'Listen to the heart of this old soldier...

I adamantly protest the richest culture in the history of the world which still incarcerates millions of humans with and without disabilities in barbaric institutions, backrooms and worse, windowless cells of oppressive perceptions, for the lack of the most elementary empowerment supports.

I call for solidarity among all who love justice, all who love life, to create a revolution that will empower every single human being to govern his or her life, to govern the society and to be fully productive of life quality for self and for all. '

Justin Dart, Jr - Last Directive and Manifesto





LASER BEAK MAN

AUTISTIC ARTIST

TIM SHARP -

CHALLENGING

STEREOTYPES

25 year old Brisbane artist Tim Sharp challenges the way others see people with autism - he exhibits around the world, has had his cartoons turned into a TV series and uses his talent to communicate his razor sharp wit.

//

His success comes from hard work and being in the right place at the right time." - Judy Sharp

When Tim Sharp was three years old, his mother Judy was told that the best thing she could do was to "put him away and forget about him". That he would never talk, go to school or have any quality of life.



Tim Sharp with his artwork lighting up the Sydney Opera House

Tim is not just a 'successful autistic artist'. Tim is a successful **artist**, and his work has been applauded by art critics across the world.

When Tim was 11, he invented a quirky superhero named Laser Beak Man, and has been drawing him ever since. His creation has been turned into an eight episode TV series screening on the ABC and Cartoon Network Australia, Asia and New Zealand. Tim has worked for Bigfish TV, ABC television (who produced the television series), film companies within Australia and the USA and a rock band from Nashville who asked Tim to produce art for their album cover and collaborate with them to write a song. Then there's the film about Tim, screened in the Metropolitan Museum of Art in New York City, his involvement in the What Am I Music Festival in Nashville, Tennessee, the fact that art has been exhibited at the Sydney Opera House, Washington DC and New York - Tim Sharp is an artistic force to be reckoned with.

Tim's mother, Judy, says that she is often asked how Tim gets these opportunities and why he is so successful.

"Most times, the answer is quite simple - hard work and being in the right place at the right time," she says.

"When Tim has an exhibition he does not just send the art off to hang on the walls, he attends the exhibition every day, often for twelve hours at a time. This is not easy for Tim to do and is very

exhausting for him especially as he meets so many people who want to spend time and talk with him. Tim realises that it is part of the process of being a successful artist and at these times he steps outside his comfort zone. This is how he has met most of the people who have come into his life with these wonderful opportunities." Tim has made his own luck.

Part of the appeal of Tim's art is that it is different from mainstream arts practice. He uses crayons, and all of his art features his character, Laser Beak Man. Tim doesn't compromise his work by trying to please other people - his arts practice reflects his humour, intelligence and happiness.

Judy says another secret of Tim's success is his attitude.

"Tim is an incredibly courteous and polite young man, who is willing to learn and get along with people," she says.

"He does not ask for allowances for his disability. Tim sees himself firstly and most importantly as Tim the artist and an equal - people connect with this."

And what of Tim and Judy's hopes for the future?

"We hope that his many successful collaborations are paving the way for others to follow and will lead for many more opportunities for other people living with disability. Tim has an extraordinary and rare gift that he shares with the world"

We agree.



A land of sweeping planes - Tim Sharp



BROTHERHOOD OF THE WORDLESS

BROTHERHOOD OF THE WORDLESS

BARRIERS TO COMMUNICATION

HAVEN'T STOPPED

THE BROTHERHOOD OF THE WORDLESS

It's an evocative image. A hand reaches up from inside a well, and a stream of words spill out - 'Big Thoughts From the Frightened Well', the caption reads.

It's one of the books by a group named 'Brotherhood of the Wordless', a Queensland group of artists, writers and poets with assorted disabilities that impair their ability to communicate. But that hasn't prevented them from publishing their own anthology and performing their works in the Queensland Poetry festival and other events and venues around Brisbane. Fifteen members have been meeting for two hours once a month for eight years, using facilitated communication to speak their thoughts.

The Brotherhood of the Wordless is probably the

only group of its kind in Australia. In addition to transforming their lives from silent isolation, the group has produced two books, a musical, a cabaret show and has performed at the State Library, Queensland Writers' Centre and the Woodford Folk Festival.

There is much to write about facilitated communication - especially when it comes to issues like justice and the ability of people to testify in a courtroom and communicate their thoughts, to the world. And for many, it is only a few years since members have experienced liberation from institutional and institutionalised care and abuse.

Immerse yourself in the words of these writers, poets and playwrights - you can find out more about the Brotherhood at <http://peter-rowe.info>

GLEN SHEPPARD

Prose written by Glen in response to a challenge to : 'finish the line three times for the following:

My body - My voice - My sex - My bones.

'My body is a flaming mess it goes in weird places and I can't control it, arms are in the air and head is nodding, tongue is hanging out with saliva dripping off the chin. My body has hands like an octopus.

My voice is loud and obnoxious it yells strange noises that drive people crazy especially my mum. It echoes in the night and drives the cat and dog outside for peace and tranquillity.

My voice pierces ear drums.

My sex is weird and wild it has burning desires of lust and danger it blows out of control like a volcano.

My bones creek and grind like a piece of machinery they move in different directions that surcome to ridiculous.

My heart weeps like a flowing stream of water.'

DAVID GOLDSMITH

The boy and the dog were looking for something to do. It was very late in the afternoon for them to be out.

'Can we go home?' asked the dog, but the boy did not understand and it was very difficult for the dog.

'What is the matter with me that nobody understands me?' thought the dog.

'I can talk to other dogs, but people do not hear me. Could it be that I have a different language to others? Will somebody please help me to understand what is wrong with me?'

The boy was sure what he needed to do was to be able to get home with the dog to help me.

'What can I do to make people understand me?'

It would be a long time before he got an answer.



DISABILITIES:

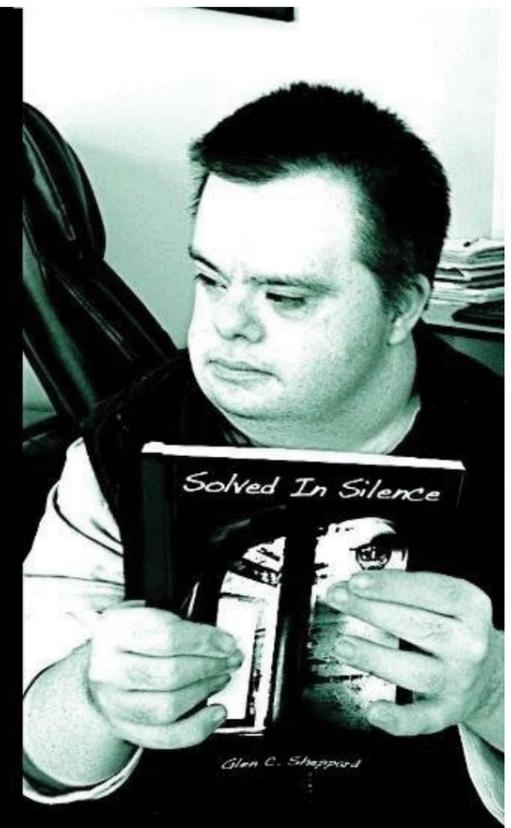
- AUTISM
- DYSPRAXIA
- CAN'T SPEAK
- DOWN SYNDROME

ABILITIES:

- UNIVERSITY STUDENT
- AUTHOR OF 3 BOOKS

UM SORRY, WHAT WAS YOUR EXCUSE AGAIN? :P

WWW.GLENSHEPPARD.COM.AU



BROTHERHOOD OF THE WORDLESS

ADRIAN KOOISTRA

Sanity

A great girl holds on to nothing but better is she for it. Her truest friend is inside. Her mind may deceive her but only to give her peace of mind. She kind of just loses herself if she is to hurt on your behalf. She might give in and lose herself to the voices instead... That sounds less painful. Pain frees us from insanity. who chooses to be sane anyway?



DISABILITY RIGHTS

BINGO

We won't pay you a dollar an hour any more, but you won't be able to sue for backpay.	It is a very old building and we do not have a lift.	The disabled entrance is out the back.	Why don't we just carry you up the stairs?	He tasered the man who didn't speak when spoken to.
We're taking your child away because you're disabled.	If I hire a disabled person, they will take up too much sick time.	Dogs aren't allowed in this restaurant.	I'm only parking here for five minutes.	Sometimes it is just kinder to let him or her go.
You won't be able to fly without a carer.	You're going to terminate if it has Down Syndrome, right?	It's very important that she makes eye contact. It's an employability skill.	You have children? Really?	We pride ourselves on choice and control - porridge or cornflakes for the rest of your life
You're going to sign a DNR before that operation, aren't you?	You can use the freight elevator. Watch out for the rubbish bins.	She'll never be a mother anyway. Let's do the surgery.	Disabled people don't come here anyway.	We don't do autistic children - there are special dentists for them.
If I make this special exception for you, I'll have to do it for everyone.	Sorry for the lack of access, but you're welcome to have a drink outside.	Yes, we can terminate the foetus at 32 weeks - it looks like it is going to be short statured	We don't know when the elevator will be fixed.	What's wrong with your child?



JOB

EMPLOYMENT FOR PEOPLE WITH DISABILITY

THE AUTISTICS' VIEW

ON THE BSWAT -

BY JOEL WILSON

Under laws for the workshops, many disabled staff are legally paid about \$1 to \$2 an hour despite Australia's supposed minimum wage being \$16.37 an hour.

Yes, you read that correctly. There's a clear gap between the supposed minimum wage, and the legal obligations by employers.

I know what it's like to be placed in a sheltered workshop. When I was 18, and living in a group home, I spent eight hours a week working at a place in metro Perth, putting velcro stickers on X-Ray envelopes. I was getting somewhat between \$5-\$6 per hour. The work wasn't hard, but I was capable of so much more. The issue was that as I lived in a group home, I was labelled as unable to work in a regular work environment, and deemed incapable of performing tasks beyond using stickers. However, that's just my story. I worked alongside other autistics, some of

whom were barely able to perform the sticking tasks. The positive was they were still given that chance to participate in a work environment. Unfortunately, businesses take advantage of the sheltered workshop scheme, or Australian Disability Enterprises as they are now called, with 300 across Australia employing around 20,000 people with disability in work that includes manufacturing, packaging, and cleaning.

The Australian Government deems it appropriate to define 20,000 Australian wages based on a label of a disability, or impairment - even though a court case in 2012 ruled that staff in sheltered workshops have been underpaid for several years, and this was a breach of the Disability Discrimination Act.

Not only that, The Abbott government last week announced it would be making a one-off payment in July to these underpaid Australians.

But there's a catch. Those who agree to the payment will waive their rights to sue for potentially a much larger, and deservable amount.

This announcement has been made just weeks after legal firm Maurice Blackburn lodged a class action seeking the underpaid funds. Maurice Blackburn industrial relations head Josh Bornstein said: "This government is attempting a shakedown of intellectually disabled people." Maurice Blackburn will be lodging a court application this week to stop the Government's scheme, and push for the correct earnings to be repaid.

The average price for a loaf of multigrain bread is between \$2.50-\$3.50. A small jar of peanut butter is \$3.50. That's \$7. On the wages some of these people are on, they'd have to work seven hours just to afford bread and peanut butter.

I hope that the rest of Australia realises that just because someone is labelled with a disability, they still deserve the rights of every other Australian; and that this no-doubtedly stressful legal process is over soon, with the right outcome - what they deserve.

The Autistic Self Advocacy Network of Australia and New Zealand committee does not condone lower wages for people with disabilities, and feels that the Australian Government are failing to do the right thing by the people involved.

BSWAT - BEWARE THE FINE PRINT

WHY AREN'T DISABLED WORKERS GETTING A FAIR GO?

Last week the Assistant Minister for Social Services announced a scheme to provide an additional payment in certain circumstances to eligible supported employees with intellectual disability whose wages were assessed and paid using the Business Service Wage Assessment Tool (BSWAT) in Australian Disability Enterprises (ADEs).

This announcement follows last year's decision of the full Federal Court in *Nojin and Prior v The Commonwealth* that the BSWAT model was discriminatory to people with disability, specifically people with intellectual disability.

An application by the Commonwealth to exempt the BSWAT from the obligations within the Disability Discrimination Act is currently before the Australian Human Rights Commission.

While the decision to recognise that people with intellectual disability who have been paid according to BSWAT have experienced economic loss is welcome, the sting is very much in the fine print which required these workers to sign away their legal rights to sue the government for back pay.

Lawyers acting for thousands of underpaid

workers will lodge a court application to block this scheme to tackle the underpayments.

Broad reform is urgently required to end use of the BSWAT, transition to the Supported Wage System, and to provide genuine employment support to people with disability to move in to open employment.

The BSWAT was always unfair as it bases ongoing wages on a strange test which tries to combine competency and productivity using a formula which is then averaged. Some ADEs are also large, profitable commercial ventures who can do better by their workers. Simply put, no one should be getting paid \$1 an hour for their work, which is what is happening now for some workers.

Most Australians would agree that it should be contributions, work value and the grunt you put into your work that shows up in your weekly paypacket, not someone assessing your characteristics using a government formula.

That's not how those making these decisions are paid and we need to ask ourselves whether any other Australians would be asked to sign away their rights to be properly paid for their work or to put up with being paid \$1 an hour.

Those who say that people with intellectual disability don't work hard or produce the same

outputs as other people clearly haven't met many. People with disability work hard and sometimes long, working well past retirement age. Indeed as a sometimes manager I would gladly trade workers in ADE's I know for some people in the Public and Community Sector I have worked with over the years which have been hotbeds of absenteeism, presenteeism and other isms which haven't even been named.

Workers in ADE's deserve a fair go and it should not come through trading off their legal rights to backpay.

Craig Wallace is the President of PWDA.



1. EVERYONE HAS THE RIGHT TO WORK...TO FREE CHOICE OF EMPLOYMENT, TO JUST AND FAVOURABLE CONDITIONS OF WORK AND TO PROTECTION AGAINST UNEMPLOYMENT

2. EVERYONE, WITHOUT ANY DISCRIMINATION HAS THE RIGHT TO EQUAL PAY FOR EQUAL WORK

3. EVERYONE WHO WORKS HAS THE RIGHT TO JUST AND FAVOURABLE REMUNERATION, ENSURING FOR HIMSELF AND HIS FAMILY AN EXISTENCE WORTHY OF HUMAN DIGNITY AND SUPPLEMENTED, IF NECESSARY, BY OTHER MEANS OF SOCIAL PROTECTION.

EVERYONE HAS THE RIGHT TO FORM AND TO JOIN TRADE UNIONS FOR THE PROTECTION OF HIS INTERESTS

- UNIVERSAL DECLARATION OF HUMAN RIGHTS

BETWEEN JOBS: JOBS AND JOBLESSNESS

Since before Christmas we have had a flurry of media around the

Welfare Review Panel formed by Minister Kevin Andrews and headed up by Patrick McClure.

Slowly, mainly through News Limited, the picture is becoming clearer with reports that the changes will focus on moving young people who are deemed partially fit to work onto some kind of temporary payment. It also looks like we could be stepping into an ongoing series of reforms.

I agree it's a waste to see young people on income support and this begs some questions: where are the jobs for them to go to; the accessible communities they need to get to those jobs and, until the NDIS rolls out fully, where are the supports they need to be ready?

I also think the question of disengagement for young people with a disability is complicated.

Many young people get into work slowly – through casual work, retail, supporting themselves through University by working at McDonalds and building a resume. They also gain heaps of skills through youth development activities ranging from places like Scouting, youth enterprise schemes and school bases activities.

In Australia many young people with disability simply don't get any of this. There is no culture of youth development and service programs specifically tailored to young people with disability like in the United States.

A backwards system of Special Schools and arcane institutions shuts people away rather than

REFORM SHOULD

FOCUS ON JOBS.

POVERTY - AND

HOW WE SHUT

YOUNG PEOPLE OUT

Changes to the DSP and possible ongoing reforms mean rethinking of the issues - and maybe a revolution on jobs for people with disability, says Craig Wallace, President of People with Disability Australia

helping us enter the world. The levels of support needed to maintain a part time job in Coles or Woolies, while they build work skills or study, don't seem to be a priority for services.

I'd like us to ask what causes and sustains joblessness? Why aren't our bright young people with disability ready and snapped up? And I don't mean by an Australian Disability Enterprise which pays them under \$2 per hour and keep them working until they are 80 – clearly someone wants us, just cheaply.

We need to look to the heart of disconnection and how we set people up to fail.

It's been noted by Infrastructure Australia (2010) that there is a link between disability and social isolation. The 2010 GSS found that people with disability participate less across all life domains from being part of a sporting team, to spectating at a sporting event, from volunteering to the arts and to even visiting a library .

The evidence is that disconnection is ubiquitous (i.e, universal) but there is also evidence that reconnecting people in one area of our life can help to reconnect in others.

You really have to hunt for work on this, but it's there. In 2009 the U.S. Department of Labor, veterans organisations and disability sports

organisations looked at the interface between participation in sports and employment. The survey found that participants in sport are twice as likely to be employed as the general population of adults with disabilities (68% vs. 33%) . That's not the sort of work that can be dismissed but I wish we had more work linking different kinds of participation in Australia.

What we do know from sources like the Hays Quarterly Report is that Australian employers want to hire people with "soft skills" as much as hard technical skills.

We know that resilience in a job is often about more than just the technical side it's about employees who can become part of workplace culture and who can have water cooler conversations.

That's why Disability Employment Services should be given a broader brief to work across people's lives to build friendship networks, involvement in recreation, sport, arts and strengthen community connection, personal capacity and independence. Their focus should be on resilience and capacity, outcomes not throughput.

We have a real challenge on our hands and that is a challenge for advocates (yes us) as well as Government. For some of us, looking at income support has become a kind of no go zone for fear of another

wave of punitive reforms and talk about protecting DSP through another Budget as if that were some kind of victory. I can well understand this, but is it really a "victory" for our movement to have over 800,000 of us stuck on low incomes with latent talents underutilised? Some people will always need income support, but is keeping people on welfare without other choices really some kind of wonderful and progressive? Or do we want people in satisfying work who can. And what about the need for a much better safety net for the rest? Do we need a rebalancing?

The issue here, really, is about poverty and economic rights under the UN Convention on the Rights of People with Disability. If there is a right to be mired in poverty, I missed the memo.

Australia's bad record on disability and jobs casts a shadow over everything. It makes me sad. 45 per cent of people with a disability live in or near poverty; more than double the OECD average of 22 per cent. Recent data suggests the situation is deteriorating, with figures showing that workforce participation with people with disabilities has dropped to 53%. We rank 21st out of 29 OECD countries in employment participation rates for those with a disability. We rank 27th out of 27 in terms of the

correlation between disability and poverty.

You could say that in Australia, the unemployment and poverty rates of people with disabilities are placing people in conditions experienced in the Great Depression.

In the US, the unemployment rate was about 25 per cent. Faced with a problem of such magnitude, the response of a newly-elected President Franklin Delano Roosevelt was to mandate continuous innovation until things began to change.

Here in Australia, we seem stuck with the same old solutions. Expecting changes to the Disability Support Pension (DPS) to create extra jobs is like trying to fix a leaky tap by getting an electrician in to rewire the ceiling. It's the wrong solution to the wrong problem and it doesn't work, but we keep doing it anyway.

It's time we had new ideas to get more people with disabilities into meaningful work. Here are a few:

- We need a goal. In their 2011 report for the Australian Network for Disability, Deloitte Access Economics points to an increase of between 191,000 and 203,000 additional people in the labour market, should participation increase by 10 per cent. If we're serious, a national goal of 200,000 jobs for people with disabilities over the next decade is reasonable.

- It's time to ask whether

policy is still in the right place. When the Commonwealth and the State and Territories split disability policy in the 90s, disability support services were pushed to the States and income support while employment programs were delegated to the Federal Government. The National Disability Insurance Scheme (NDIS) is shredding the divide so perhaps it's the right time to ask whether there is more that the States, Territories and Local Government can do. These bodies have leverage, they procure from industries that provide many base level jobs; why not make employment of people with a disability a national priority through COAG?

- Attitudes are also important and governments invest in awards, campaigns and quality work to build the business case. Yet we have surprisingly little hard evidence about what attitudes are and what might actually work to shift them. Governments should invest in an internationally benchmarked national survey on community attitudes towards people with disability to formulate an action plan for better employment opportunities.

- To give things a kick start, let's have an employment target in the Australian Public Service. In the US there are employment programs that support people with disabilities to serve as interns

in the White House and on Capitol Hill. Why can't Australian Senators and Members of the House of Representatives utilise the skills of people with disabilities in the work of our Parliament or in their electorate offices through paid parliamentary internships? For every MP and Senator this would mean a total of only 226 jobs. But what an effective way to 'walk the talk' and show every constituent, business and lobbyist that this time we are serious and here is what employees with disabilities can do?

- We should recognise the power we all have as customers. As the backlash against Myer showed, disability is now a retail customer force to be reckoned with so why not put that to good use?

- The suggestion by Former Federal Workplace Relations Minister Bill Shorten to introduce mandatory annual reporting by medium to large private employers, including about senior positions, was a good one as it could use the leverage of this new marketplace.

- The 2009 ABS SDAC found that people with disability participate less across all life domains, for example from being part of a sporting team to attending a sporting event, or from doing volunteer work to visiting a library. A US survey conducted in 2009 shows that

participating in one area of life, like sport or the arts, can be the tipping point for people to re-engage in employment. Disability Employment Services could provide assistance to build friendship networks or facilitate involvement in recreation, sport or arts to strengthen community connection, personal capacity and independence. Why can't we try and see if this works?

- As the NDIS changes the funding game, we might also ask whether the principles of personalised budgets which are shaping the NDIS could apply to Employment Services. If services don't get people jobs, we should be able to take funding to another provider, including job agencies outside the network, or even 'unbundle' money directly to an employer to provide job opportunities with in-house support. Why not?

- Instead of tinkering with the entry into DSP, the new coalition government should look into using income support to help people sustain a job as they build assets and financial capacity by allowing people with disability moving into entry level positions for the first time to retain their DSP for a period of at least 6 months. Again, why not try it?

- We need to address the barriers that are stopping people getting to work in the first place. Is there a better example than the horrendous

mess that is accessible transport for people with disability? Here we are in 2014 – more than a decade out from the Sydney Olympics which promised to tackle our inaccessible infrastructure and our trains and platforms are still inaccessible. Sydney is our biggest city – a big sprawling metropolis where you need to commute to get anywhere – and the trains don't have ramps, the platforms have stairs and accessible buses are a slow moving joke with change having timeframes going out to 2032. Taxi's? I hope you have a wallet the size of Texas then.

A wonderful advocate called Pauline David brought this into sharp relief by inviting Sydney Daily Telegraph readers to share her nightmare journey for a day. I'd urge you to support her petition on change.org calling on the NSW Transport Minister Gladys Berejiklian to spend a day in a wheelchair on her own network. You can sign it here -

<http://tinyurl.com/oe2jcb>
Of course former Mission Australia boss Patrick McClure, is no stranger to these issues having been Chairperson of the Australian Government's Reference Group on Welfare Reform in 1999–2000 which produced a key report titled 'Participation Support for a More Equitable Society' (2000), also known as the McClure Report.

While Mr McClure produced a strong report, addressing a number of these issues, more than a few commentators felt that the Government of the day cherry picked the report, rather than tackling a breadth of recommendations that acknowledged the intractability of employment barriers for many people with disability.

Having been called to the task again, the best thing that McClure might do is to plumb the true depth of the jobs crisis and fulsomely describe the collective failure of any Government of recent times to carve out an ambitious, meaningful or coherent agenda.

In doing so he might create a climate for change through continuous innovation – a context where we provide permission for people to throw out the old models and try totally new ones, such as purchasing economic participation outcomes. In the words of FDR, "It is common sense to take a method and try it. If it fails, admit it frankly and try another. But above all, try something."

Our project in disability rights is not completed by the NDIS. If we are bold, this could be the start of a revolution on jobs, a logical next step twinned to the revolution on supports we've had through the NDIS.



THE RIGHT TO WORK - AND BE PAID FAIRLY

The law says that all people have the right to work and to be treated fairly.

In 2011, two men with disabilities, Gordon Prior and Michael Nojin, took the government to court.

They said that the test used to work out the wages that they were paid was unfair.

The test is called the 'BSWAT' test.

This is how the test works.

If you work in supported employment (at an ADE or sheltered workshop) there is a basic rate of pay that is the same for everyone.

But then the government can tell you to do the BSWAT test.

If you fail the test, you earn less money.

Mr Nojin and Mr Prior took this system to court and everyone

agreed that using the test was wrong.

The test discriminates against people with disability.

But it is still being used.

10,000 people with disability still go to work every day and get paid lower wages.

The wages are worked out using the BSWAT test.

Mr Prior changed his job. He used to earn \$3.00 an hour, and now he earns \$15.00 an hour.

The government now says that they will give workers who have been disadvantaged a special payment.

But the workers won't be able to sue them for the money they are owed in backpay.

Many people think this is unfair. They think people with disability should be given a fair go.

DO YOU WANT
TO KNOW MORE
ABOUT THE
BSWAT TEST?

If you are affected by the BSWAT test, or if you need to know more, email noni.lord@aed.org.au or to contact the AED on (03) 9639 4333 or at <http://www.aed.org.au/>

LAW



ADAM COPE: ARMED NOW WITH HOPE

I was born quite young actually, before my first birthday. Until I was eleven I was isolated from life, tucked away safe and sound in a Day Training Centre. At this time I was unable to communicate in any way, other than by using bad behavior.

When I was eleven I was enrolled at my local primary school and the "cotton wool" was gradually unwrapped, exposing me to the pain and joy of the real world.

It wasn't until I was thirteen that I participated in a momentous appointment at DEAL, with Rosie Crossley, that revolutionized my life. It was here that it was found that I was not entirely stupid, only a little bit. I learned to communicate with a keyboard

and my life has not been the same since. Now I was not only expected to attend regular school, I had to do the same work as the other kids. This took a lot of effort. Quite apart from the challenge of the workload, I also had to put up with the prejudice of many of the staff and students. However, with the support of wonderful people such as the deputy principal, Treva McGregor, some of the teachers, my integration aides and my fabulous parents, I weathered the storm and actually managed to enjoy some of my schooling.

Having finished my VCE, I started at TAFE with a writing and editing course. I did one year of this but due to my scaring away my lovely carer, Emily, I never completed the course. Now I really don't want the pressure of organized

ADAM COPE
TALKS ABOUT
POETRY - AND
RED TAPE

Adam Cope is a poet with a difference - not because of his disability, but because of the extraordinary power his poetry holds.

Adam has published several books of poetry - you can find out more at www.adam.org.au/books

learning, I've had enough.

Over the years I have written a lot of poems. Many of these inspired by my love of the Australian bush and

many by the struggles of living with a disability. The fact that my Grandma is a very good poet has also inspired me and encouraged me to keep trying.

Nowadays I don't write much without being pushed into it. I'm not sure why, maybe it's not having all that teenage angst that is the problem."

'TERMS OF LIFE' - ADAM COPE, JUNE 1988

Adam wrote the following poem, Terms of Life, when he was at Secondary College.

It was published in 1992 by the Victorian Education Department along with other student's works and articles supportive of the successful 'Integration Program' running in Victoria at that time. Artwork by SA artist Paul McCoy.

Alone in dreams and wondering
if life might drive you on
and seek out answers
known only to god.
Gone forever the wishes of
youth as when alone you weep.
Despairing from worldly
thoughts
as life departs from view.

As presents of time escape
and told stories become
unpleasant.
The wasted time reveals not
strengths
but plays on each weakness
with hellish results.
Strengths easily held back by
worship
of special and different
despite being the same
inside.

Domed and secure I did little
as life went past.
Held together by hope
escaping from a sceptical world
into the depths of my dreams.
Justice escaping again as
charity based



schools grew richer
with clients
Not people instead.

Sweating for life I saw
real schools go past,
kept from me by bureaucrats
and prejudice.
Longing for deals with
worth I grappled with past
thoughts
Fighting each day for
relief.

Life would have been lost
except for my family and
friends

Cutting through red tape like
a warm knife in seasoned
butter.
Released at last.
I arrived at my lovely real
school.
Quickly warming my brain
with fast flowing food.

Suddenly life had new meaning
as the kids saw me as a person
and not someone who asks for
charity.
Easily warmed by their wisdom
and encouraged by their hope I
grew up.

NOT JUST ANY POET - CONSTRUCTING SUBJECTIVITY

AN EXTRACT FROM 'ARMED NOW WITH HOPE' -
UNIVERSITY OF BALLARAT'S GENE
MARKS SPEAKS ON ADAM COPE AND THE
CONSTRUCTION OF STUDENTS
WITHIN INTEGRATION

Adam Cope is a poet. And not just any poet. He is the sort of poet that makes the soul of the listener cry out in empathy. He is the sort of poet that ensnares the sound of the temperate rain forest that waits outside his door. He is the sort of poet who captures those moments of pain and love, and preserves them as glistening stalactites. He uses words to explore his world, and ours, in ways that most of us can only dream about. His language is precise, pithy and distinctly his own. His insights have the power to dredge up emotions long buried and lost. His poetry reduces

all that know him, and many who do not, to tears.

Adam Cope is unable to speak, and has never spoken. He is a young man with a disability known as tuberous sclerosis. Among other things, this causes, for Adam, epilepsy, tumours on his brain, and apraxia. The disability was diagnosed when Adam was four months old, and his parents were led to believe that for Adam, it also brought intellectual disability.

Adam started his formal school at a special school called Minibah. Minibah was a day training centre for students with severe to profound intellectual disabilities. At the time Adam



"Armed Now with Hope": the construction of the subjectivity of students within integration
By GENE MARKS

began school, special segregated settings were considered to be the right educational location for children who could not communicate. And Adam certainly could not successfully communicate. There is little doubt that he was often a sad and angry child, who did appear to have an intellectual disability. With first, the acceptance of integration in Victoria, and second, the advent of facilitated communication for students with communication difficulties (see Crossley, 1990; Biklen, 1990), Adam's world changed. People around him, his family and teachers, became aware that Adam did not have an intellectual disability.

How then, has Adam constructed his own subjectivity? Does he construct his identity as resistant or compliant? Does he also think of himself and his disability in terms of binarisms?

And how does he view the inscription of his body as disabled? It seems from an analysis of his writing that when he was unable to communicate, Adam saw himself as compliant and oppressed, although his overtly difficult behaviour at the time would suggest otherwise. In an early poem *Fall in Down to the Ground*, Adam painted his life as a picture of despair. He constructed himself as a mole—whereas the mole is afflicted with blindness, Adam was unable to speak. He could not communicate effectively, and no one could understand him. As “Old

mole in the hole”, he was safe, anonymous and hidden. Even his imaginary friend Jill did not join him in his hole. He was alone, unreachable, but still in need of assistance. “Help a nobody please.”

Years later, in 1990, Adam reflected again on his inability to speak, and the burden this caused him. In *Imagine*, he wrote:

‘Lost each day and waiting possibly for life, but not knowing if it’s there. The mute arrives and listens.’

This is a far more sophisticated depiction of the way Adam constructs himself.

With sleepy eyes and lovely tries he tussles and turns away, for life has passed him by. Trying yet another time to weep and laugh as well, he passes yet another time and wonders if life’s near.’

Adam is challenging us to imagine what it would be like to be mute, to be Adam, and to have the world pass by, and wonder what life would be like. How often has the world passed Adam by? And what of the child who had no way of telling? Was there any less suggestion that he constructed a view of himself all the same? And what of the changes that went on in his head, when those around him discovered that he was not intellectually disabled at all, as they had once believed? How does one make the shift from constructing oneself as intellectually disabled, to constructing oneself as a writer?

The two identities do not sit easily together.

At times, for Adam, the contradictions have seemed just too great. In 1987, he was struggling with a combination of puberty, and a lack of belief in his own ability.

“Just learning at schools is good, but I need a break. I am frightened of falling back when getting weary.” (10 May, 1987)

Indeed, when things became too stressful, Adam pleaded to be allowed to adopt his old, safe identity, to become the mole again. While reprimanding himself for inappropriate behaviour at school, he asked his teachers to let him be “the poor little disabled boy”.

“I find it is very difficult to concentrate when there are other things going on around me. Instead of behaving like an idiot I will have to try to justify being a poor little dear disabled boy. Please let me play the poor little disabled boy when things get difficult. Perhaps I ought to play the likely lad instead. When I am feeling better it is lots easier.” (11 March, 1988)

That his teacher was unsympathetic shows a marked lack of understanding of the conflicts Adam faces when constructing his subjectivity. Adam’s persistent descriptions of himself as “weary old me” or “weary Adam” should have told the teacher much about the way Adam felt.

“I really get sad knowing that there are kids who have intelligence like weary old me.

Tasks are made often awfully hard with Apraxia and they are worse when people say I cannot do them. What I ask always is that we look more at people and less at the worse aspects of their disability. Although disability deserves knowing about it does much damage psychologically if it is given prominence. Real living is having the same experiences like everyone else.” (14 March, 1988)

“Lately I have been feeling a bit less pleased with being at school. I have all queer thoughts which I look at as pressure of work. When I got sick I thought about having a very dark future as life was hard. Sad just learning about a lot of things when I get depressed as work is heavy going. I am letting people hate working with me because it is easier if I plead idiot.” (25 March, 1988)

Adam did not entirely succumb to the desire to (re)construct himself as “idiot”. Instead, he wrote his way out of his depression.

‘Domed and secure I did little as life went past. Held together by hope escaping from a skeptical world into the depths of my dreams. Justice escaping again as charity based schools grew richer with clients Not people instead. Sweating for life I saw real schools go past, kept from me by bureaucrats and prejudice.

Longing for deals with worth I grappled with past thoughts Fighting each day for relief.’

He wrote positively of how life was now:

‘Armed now with hope I warmed quickly to life’s joys Stopping only once to look back and weep for my friends left behind.’

Adam constructs his subjectivity now as an adult, and as a poet; as a political being, and as an environmentalist; as a student, and as someone who has much to tell the world.

‘WINDOWS Kisses washed with water wrestling from the windows of my mind Wasted worries lest I wear out my time and chances of attacking all joys Ashed past and assumptions last made and proven wrong Windows that open and wonder all of whom ask questions Windows which close and shut off those mindless thoughts Windows restoring my walls of

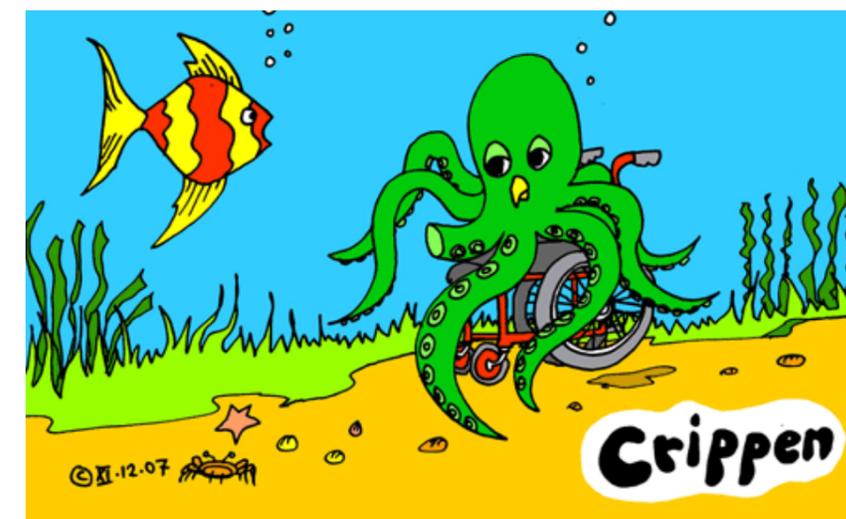
stone built firmly on life’s bastard ground Sandwiched between my fascination for questions and answers not known

Laughing at reasons which are known only to those astute beings

Whom life’s windows are open and not closed with shuttered walls.’

He constructs himself standing at an open window, with the world in front of him.

Adam may not be, and is not, typical of all students who have been labelled as disabled, any more than I am typical of all academics and tertiary teachers, and you, my reader, are typical of all readers of journals about disability. But the way I construct myself says much about all academics, and in the same way, by listening to Adam, we can learn much about the way students construct themselves. And in many ways, these constructions seem to be far different from the way they are constructed by the policy documents.



WOW, HE SAID

DAVE HINGSBURGER ON LIFE,
LOVE AND DISABILITY



“

*I felt an honour
and a privilege to
be in a position
where I could
initiate the
conversation that I
needed then, now.”*

I told someone I was gay the other day. Out of the blue. Bang! There I was saying, “You know I’m gay, right?” His face registered shock, “You?” “Yes, me.” I don’t do this often because I don’t have to - pretty much everyone knows. So it felt odd, pushing the closet door open and letting it bang shut after me again. This time, though, I came out strategically. I was just in conversation with a man with Down Syndrome who was talking with me, struggling with the fact that he was attracted to, and had kissed, another man. He thought he was in love. He was aching with pain, it was all wrong, he was dirty and sinful.

I couldn’t bear watching him. I couldn’t bear remembering the pain of feeling shamed for feeling loved. I couldn’t bear watching him hurt. So, I said, “You know I’m gay, right?” After he expressed his shock, I asked him if he had noticed Joe - the man who was often with me. He said, immediately grasping, “Joe is gay too?” I told him that we were both gay, we both lived together, we both loved each other. I did this in the calmest most matter of fact voice that I could muster. I wanted it to be presented as if it was just another simple fact, not some big revelation. “Wow,” he said. There was a long pause as he thought. Then he said, “I kissed a man.” I nodded, knowing he wasn’t

done. “He’s my boyfriend.” His eyes flicked to mine looking for something. I said, “Joe is my boyfriend too. I kiss him too.” “Wow,” he said. We then chatted a bit and he learned that I lived a regular life, in a regular apartment and did regular things. I just did them with another man. He asked not a single question about sex, he just wanted to know about the pattern of our lives - did we have friends; did our families mind; were we happy. I asked the questions simply and honestly.

When we were done, his questions answered, I sat there and thought about this conversation and about how much I would have loved to have had it when I was a young man, I wished for such a conversation. I felt an honour, and a privilege to be in a position where I could initiate the conversation that I needed then, now. Then, as he was getting up to go he turned to me and shook his head in amazement. “Wow,” he said.

Dave Hingsburger (at left in photograph) is a Canadian author who uses a wheelchair for mobility. Check out his blog at <http://davehingsburger.blogspot.com.au>

ROWAN'S VOICE

ROWAN'S VOICE WAS NEVER
HEARD - AND SO
WE INCLUDE IT HERE

Much of this edition of Starecase has been about 'voice'. There are other voices missing from the conversation – the voice of those who are trapped and of those who have fallen.

They are the people living in institutions and boarding houses; the people who are unsupported by service systems. Those who have been murdered or neglected, or simply left to die.

The last word in this publication goes to Rowan Wheaton. Rowan was an articulate young man with autism. He hanged himself at a state-fun facility using a sock suspended from a door handle in April 2006.

Rowan has a presence on the internet, but it is not his own. There are news reports that slam the inadequate treatment Rowan received at the hands of the state. His parents tried desperately to find adequate care and to get him help. The Coroner's report is a litany of system failures, by both health and disability systems – and Rowan's father says that he was luckier than most.

Rowan died a month after he wrote the below letter of complaint, which was included in the Coroner's report. The Coroner said that the letter

provided insight into Rowan's sense of justice and fairness.

In his complaint, Rowan spoke articulately about the clashes he had with another resident, and the way he was treated by staff. A month later, the social worker at the facility decided he wanted to sleep undisturbed, and turned off the house alarm.

That was the last act of 'care' that Rowan received – four hours later, he was found slumped against the door with a sock tied around his neck and secured to the door handle.

Rowan was eighteen years old.

Nobody listened to Rowan's voice then.

Perhaps they will now.

'Friday, late afternoon and early evening we were figuring out what to have for dinner. We decided to have a meat and vegetable pie. Alex decided he was going to cook the pie still concealed in its box. I told Alex that he couldn't cook it that way and he wouldn't listen. I kept telling Alex that it wasn't safe but he refused to take it out. So I took the box out of the microwave and I tried to open the box and take the pie out. Alex grabbed the box and tried to take it from me, kept telling me to let go of the box. I kept telling him that it wasn't safe but Alex wouldn't listen. I saw on TV a show called Brainiack, on the show they did an experiment that showed a can of baked beans being put as it is without opening it and the microwave being turned on for a couple of minutes. The microwave blew up, spraying lots of baked beans everywhere. Veronica stood in and said "both of you go to your rooms".

Alex stamped off to his room, but I refused to go to my room. I tried to explain to Veronica that what Alex was doing was against his own safety and that I was trying to prove that I was right, but Veronica wouldn't listen. She kept to telling me that I wouldn't appreciate it if Alex tried to tell me what to do and that I couldn't tell Alex what to do either. I pointed out to her that wasn't the point, but she still wouldn't listen. I was really pissed off, and livid, and frustrated because I wasn't being listened to, Alex could have blown himself up (and microwave) or set the house on fire. Knowing that I wouldn't be listened to by Veronica, she didn't even ask what was going on by the way, I



wanted to get the pressure off my back, so I turned around and ran out of the house. I knew Veronica would call the Police, but I didn't care. After walking endlessly along the beach for a few minutes, I decided to turn around and go back. After I got back to the house and had dinner, Veronica called the Police and told them that I had returned.

On Sunday in the late afternoon, Veronica had a discussion with me. She told me she wanted an apology and explained that I was wrong and that I grabbed the box from Alex and said that I considered myself to be right all the time. I was absolutely livid. I couldn't believe what I was hearing, so I started raising my voice, and as Veronica kept at her point less explanation, I started shouting, and calling her swear

words. So I turned around and ran out of the house, Veronica called the Police again, and when I got back Veronica told me that she rang the Police and asked them to come and have a talk with me. The Police told me that it was not only Southern Junction Community Services (SJCS) policy that I was not allowed to shout and swear at staff but also that it was law not to shout and swear at anybody. I knew it was pointless trying to get through to anybody. So I went to bed without dinner, Veronica removed the TV and the hired videos from the TV room as punishment for speaking to her inappropriately. I knew no one would listen apart from my parents. I thought it was ironic that such a person would ever punish everyone instead of asking what had happen and trying to work out

who the culprit was, she did not care. I want you to do something about this little issue that has grown to a bigger more complex situation. If you agree with me, if you understand I would like you to make it rule that if such a situation ever arises again that the staff not punish both but ask what happened and judge who is incorrect. I would also like you to, if it is not too much trouble, talk to Veronica about the situation, although I wouldn't mind having a discussion with you first just to get my side of the story. I suggest you tell Veronica to judge us evenly next time rather than punish us first.

Yours sincerely, Rowan Wheaton.'

* It is estimated that young people with autism are 28x more likely to commit suicide.

WELL, THIS IS EXCITING.

WE'RE GETTING STREET LEGAL.

A few months ago, we didn't exist.

But we've received enough interest and attention that we're forming a legal entity so we can accept advertising and financial contributions. We need your stories and poems and photographs and thoughts and ideas and support. If you want to get starecase-famous, email us now.

Email us at starecasenews@gmail.com