

SRV *in action*

Literary Edition

May 2017

PRN

Prue Gorman

THE PHOTOGRAPHER

John Buckley

A CINDERELLA STORY

Citizen Advocacy South Australia

Editorial

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SIX HUNDRED & FORTY HOURS

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SRV in action

An initiative of **Values in Action Association Inc.** to assist people make the links between the theory of Social Role Valorisation and how it can be used in our work and our lives. We are assisted by our colleagues in other local groups as well as the Australian and New Zealand SRV Group.

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Values in Action is a small unfunded incorporated association in Australia (Brisbane, Queensland). It hosts SRV and SRV-related events as well as working to develop SRV application and the emergence of next generation leaders.

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Throughout this periodical the following style formats are used:
Italics are used for both emphasis and for SRV concepts.

Direct speech is italicised and in single inverted commas.

Quotes and unusual expressions are in 'single, inverted commas'.

Chicago 15B referencing is used.

References available upon request.

VALUES IN ACTION ACKNOWLEDGES THE TRADITIONAL CUSTODIANS OF THE LAND AND OUR GRATITUDE THAT WE SHARE THIS LAND TODAY, OUR SORROW FOR THE COSTS OF THAT SHARING, AND OUR HOPE THAT WE CAN MOVE TO A PLACE OF JUSTICE AND PARTNERSHIP TOGETHER.

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values in action association

EDITORIAL

STORIES - OF GREAT VALUE

by Greg Mackay

Yes, we've departed from our usual format!

Why, you ask. Why a literary/story edition?

The answer is not simple (as if anything is). A whole host of matters encouraged this edition.

Perhaps the most influential, and one that has been on my mind for 18 years, is seeing Professor Wolfensberger's behaviour.

Fortunately, I was able to visit the U.S. in 1999, firstly to travel to Indianapolis to participate in the first and only presentation of the 4-day Advanced SRV event, a precursor to SRV10 that now forms the key SRV theory event.

After the event and following an enjoyable drive and stopover in Pittsburgh, I spent a week in Syracuse at the Training Institute with Professor Wolfensberger and Susan Thomas.

And of course who wouldn't be impressed with the massive array of books and other written resources then housed at the Institute? These resources were, until recently, curated by Cameron Boettcher who has recently left the role, at the University of Nebraska within the McGoogan Library of Medicine in Lincoln, NE - well worth a visit. See Edition 4 for Jane Sherwin's introduction to the collection - www.viaa.org.au/resources

However, it was at Wolf's home that I truly began to see the value of fiction in understanding how society sees and deals with devaluation and wounding, responds to roles, and creates hope and opportunity.

Wolf's personal library included many novels and other fictional writings depicting people with disability, older people and people from a wide range of devalued groups. All contained Wolf's summary and critical analysis.

Since then I've come to appreciate and value the place of story and literature in our development, thinking, and heart-orientation. In my own ethnic

tradition, story takes a central role. For example, the Scottish Storytelling Centre encourages, supports and facilitates storytelling in families, communities, places of learning and natural environments. They also recognise and honour several special kinds of storyteller:

Tradition Bearers - those who have preserved and are passing on older traditions of stories. They are the Honorary Founders.

Community Storytellers - those who share stories in their communities or through their work contributing to human well-being and quality of life.

Professional Storytellers - those who travel across Scotland and exercise their storytelling craft as a paid profession.

I would like to think that we mirror or at least approximate this schema within the SRV community.

This edition presents stories, poems, and haiku. It celebrates life; it recognises the profound sadness of devaluation, it provides ideas for applying SRV and using it as a lens, and it poses questions. A heartfelt thank you to the writers; I've greatly appreciated reading your work. I hope you, the reader, does as well.



I shot the serif.

PRN

by Prue Gorman

Prue Gorman is Executive Officer of Community Living Project, a disability service provider in South Australia whose work has been shaped by SRV theory for over thirty years. Prue is committed to strengthening the capacity of people to build good lives in their local community, through facilitating individual, family and staff leadership. Her roles include community choir member, traveller, avid horse lover and adventurous rider.

*Invaded by tubes, your face
I've known forever, so like our mother's
is being rewritten by labels and the uniformed
custodians of your health*

*Next door a fall, fractured ribs
ventilation and distressed family
vie for the authority of their opinion*

*A cleaner in blue, waving her angled mop as to a bull
in a ring of pulsating beeps and multihued trails
marking the passage of blood and essence.*

You thank her, gently, for her time.

*Dust mites and bacteria swarm, unperturbed, across the polished arms of your hospital bed
as you struggle for breath
and our eyes
lock.*

*Sister, grandmother, friend, teacher.
Funny, clever, wise.
Vulnerable.
Undone by charts, by science, by strangers, by disease
Patient. Diagnosis. Intubate. Intern.
Names that depose my scant authority and demote my lines
to an extra in a play
that is rapidly*

losing the plot.

THE PHOTOGRAPHER

by John Buckley

John Buckley is a creative writer who has experienced the good and bad aspects of expectation. It is his wish for others to recognise their role in the limiting and expanding of expectation for all.

There once was a boy who was different. He wore the difference like clothing. He was different from his family, different at school, different in his community. His difference held him apart. His community was wary, his school was scornful. His family loved him and accepted his strangeness but he felt apart. He knew his difference was difficult for them. He went through life wordless and separate. His family sought connection – he knew of their efforts but was unable to respond as they hoped.

One birthday he was given a camera. His father showed him how it worked. They spent time walking together, finding something to photograph. He enjoyed this time with his father. The pictures were shown to his family and they talked and speculated about the subjects – he enjoyed this even better. Taking pictures became part of his day – pictures of people, places, dogs, flowers, children, birds, trees – everything around, he photographed.

Every day his family would look at these pictures and tell stories about them.

He would sit and listen and be enclosed in their fun. He laughed as they imagined funny stories, and was sad when they recognised a subject of sorrow. He felt close to them for the first time. His family, yearning to be close, encouraged him to keep taking pictures. He became more proficient with practice but even though they praised his work, he enjoyed their storytelling best. They sat each night enjoying each other's company. He felt part of them, part of the family.

A DEATH IN THE FAMILY

by Fiona Cameron-McGill

Fiona has held significant leadership roles in human services and in SRV-related groups. She currently teaches at the Australian Catholic University. Fiona lives with her partner on Bribie Island, and works actively on environmental matters including having purchased a large tract of untouched bushland which Fiona and Richard use to encourage the resurgence of koalas and other native life.

The sky collapsed and clouds fell to earth. The tide smashed the shore and the sand scoured out the ground. The trees groaned and crashed to the ground. Birds screamed, wheeling in alarm. Or so it felt when Mary died.

She died peacefully in hospital, with her sister and niece by her side. She'd been there for three weeks while they diagnosed and then tried to treat her breaking heart.

She'd called me one evening to say she thought she needed to go to the hospital.

'Are you sure Mary? You know what they'll be like there.'

'Yes', she said, 'I'm in pain.'

I hurried around to her house with all the Power of Attorney documents. She was in severe pain. Not a heart attack. She thought she might have pulled a muscle. She'd been organising the pot plants on the veranda and some of them were very heavy.

We jumped in her car ...

(She always asked me to drive her car when we went to medical appointments. Something about her paying her way, not inconveniencing my partner by taking our car.)

... and rushed to Caboolture Hospital. The Emergency Department triage nurse was really good. She hurried us in and took all the documents to photocopy. The Emergency doctor was great too. He did his examination thoroughly and asked Mary lots of questions, respectfully, and with a real interest in her answers.

'I don't want to die', she said. 'I think I've got a bit more living in me yet.'

And she did. Mary was full of beans. She lived alone in a little rented beachside fibro cottage. She loved her garden and was always to be seen pottering about. Her grevilleas were renowned: magnificent flowers almost all year. She loved the trees, especially the old man banksias across the road in the park. She loved all the bird life and fed the butcher birds every morning while she had her coffee on the veranda. They were cheeky chaps and even flew into her house to find her if she was late with their breakfast. She loved the sky and the sea. I remember attending a turtle hatching with her. Mary and I couldn't resist helping the tiny little turtles as they frantically flapped their way out of the nest and down to the shoreline. And Mary started the Moon Watch – the Luna Tics we

are called, who gather every month at the beach to howl at the full moon. She knew astronomy and was always ready with information about the Blue Moon, August Moon or eclipses.

She had always lived alone and never married. But she was the main contact person for her family. She was the one who kept in touch with all the nieces and nephews, cousins and old friends. She belonged to the local environment group, a music group, having taken up the violin in middle age, and a painting class. Mary was friends with everyone. Everyone knew her. She lived in a real community.

I told the Emergency Department I had been given Power of Attorney for medical matters, by Mary. She didn't trust doctors. She'd had a lot of bad experiences. But so far, everyone was attending to her needs very thoughtfully. They decided to admit her and do further tests to see exactly what the dreadful pain was about. At least here, Mary could get pain relief. I went home, planning to come back first thing in the morning.

When I returned, Mary was in a ward and they had determined that her pain was caused by an ulcer on the aorta – the main artery from the heart out to the body. She had fairly good pain relief and was feeling a little better. But the nurses had called her nephew, not called me, and the dietician had been in hassling Mary about filling in the meal request forms. I reiterated with the nursing staff that I had Power of Attorney for medical matters, and would be responsible for contacting the family, at Mary's request. I also asked to speak to the dietician about Mary's food needs. Mary had complex food allergies and intolerances. She was paper thin and had carbohydrate and fodmap problems, amine allergy and dairy and wheat intolerance. She had been struggling with these problems all her life. She was very careful with her diet, made her own bread, shopped at the local wholefood store and prepared nutritious meals for herself. The dietician had accused her of being resistant and fussy and demanded that she eat the yogurt, weet-bix and milky tea she was given for breakfast. Professionals know better than old women.

One morning, Mary had come to me, as she often did, to chat about the various issues of the day. We were talking about her difficulties with doctors not listening to her and not paying attention to her

concerns.

'That's such a problem', I said. 'I see it all the time with people who the doctors assume are not as important as others. They think "You're just a silly old woman. Your health doesn't really matter – you're going to die anyway. And what would you know? I'm a doctor. I know better."' (I chanted). 'I could come with you to the doctor if you want', I suggested.

She pounced on my offer. 'Would you do that?' 'Sure' I said. 'No problem'.

We then embarked on a round of doctor visits. The GP for referrals. The neurologist, to investigate the funny pain in the back of the head – 'normal pressure hydro-encephaly'. Repeat visits to the eye doctor – 'macular degeneration' injections. 'I don't want to lose my sight', she reiterated.

The GP straightened suddenly in his chair as I followed Mary into the consulting room.

'This is my Power of Attorney for medical matters', she announced.

He was visibly stunned and according to Mary, his demeanour changed markedly from his usual lackadaisical, literally laid-back approach to her. He actually paid attention to the questions we had written out together, and prepared referrals as I directed him for the investigations that we requested. I would have to say, after several visits to him, he was the laziest doctor I have ever met in my life and I've met a lot of doctors.

Mary had already been told she had arteriosclerosis – hardening of the arteries. Her blood pressure was astronomical and impossible to treat. That accounted for the pain in the head. She walked regularly to keep the blood flowing. To see her trotting up the street every morning to buy the newspaper, you'd never have thought she was in her 80s.

Mary had asked me to be Power of Attorney for medical matters because, despite her connection to family, she didn't feel she could trust her relatives. She was from a large family. Her mother had kept her at home as the designated daughter companion. When Mary had tried to rebel and leave, her mother had her committed to a psychiatric institution, as relatives could do in Australia up until the 1960s. Mary escaped and fled to New South Wales. The 'mentally ill' label had dogged her for many years. She was the black sheep, the spinster aunt, the enviro-nutter of the family. She struggled with the negative assumptions of her brothers and sisters. The devalued status of mentally ill person was now being compounded by 'old

woman'.

In the hospital ward, I asked Mary if she wanted me to contact the family, and friends on Bribie. She said yes, so I began the task of calling everyone to let them know she was in hospital. Everyone came. She asked me to 'schedule' them as she was getting very tired with so many people in her little hospital cubical all at once. So, I worked on my laptop in the waiting room adjacent, and marshalled everyone to visit in 2s and 3s. Her sister and a couple of nieces flew up from Melbourne. A brother and sister came from up the coast and a brother from Rocky started on the drive down. Her closest niece was there every day. Another niece flew in from London. All the Bribie friends popped in.

Mary got worse. She developed a bad cough. They tried to treat the blood pressure to relieve the pressure on the aorta but it just sky-rocketed and then plummeted uncontrollably. They put her in the Intensive Care Unit, in a closed room. We had to wear masks. They said she had a form of tuberculosis.

I kept checking with Mary if she wanted the treatments being delivered – there were tubes in every orifice and machines whirling all around. She was unsure but certain she didn't want to die. The VMO was a little chap, who arrived every morning with his entourage of Residents and students. I asked him if seeing a Gerontologist might be a good idea. He was affronted. 'I can deal with all these problems.'

Far be it for me, a mere lay person, to express an opinion. Mary's acupuncturist got a worse reception. She came to see Mary - she was a good friend - and gave her a massage. The doctor was outraged and hinted at quackery. She gave as good as she got and told him she knew enough not to provide acupuncture in the hospital without permission. The hospital is an institution all its own, with rules and procedures you dare not contravene. The hierarchy is well-understood by those who work there, and patients are definitely at the bottom. Four times I had to tell nurses and doctors I had Power of Attorney and they were to contact me first. Four times they contacted various relatives, friends and associates with information Mary didn't want shared. They continued with intensive invasive treatments. Mary continued to be ambivalent, and to look and sound more ill.

In the mean time, I had to travel interstate for work. Finally, the nursing staff 'got it' that they must call me first with any issues. Mary asked them to call me in Sydney. I could barely hear her, she was so faint and breathless. They were proposing to move her to

another hospital to operate on her aorta. Open heart surgery??? On an 82 year old with out of control blood pressure???? I asked to speak to the VMO. He agreed that it probably wasn't the best idea. She'd probably die on the table. Mary said he'd come to her late one afternoon and badgered her to make a decision immediately to have surgery. She was flustered. She didn't want to die but she wasn't sure it was a good idea to have surgery. We decided to say no.

Then north Brisbane flooded. I was trapped at the airport. The hospital was surrounded by a moat. I had to get back to Mary to find out what was going on before it all got out of control. If only we could trust the medical profession to do what was in a person's best interests – not just to apply the technology, because it's there ...

By the time I could get into the hospital, they had decided the treatments weren't working. 'I told you my blood pressure was untreatable', Mary reminded the doctor.

'Yes', he gallantly admitted, 'We were probably killing you with the treatment.'

A big admission. They aren't bad people; they're just doing their jobs. But their professionalism can get in the way of their humanity.

Mary asked me to help her prepare a list of the help she'd need at home. She didn't want her niece Moira doing everything, so I said we needed the Social Worker to organise some Home Care. We put in a request. She was planning to go home and I was going to do whatever it took to get her there. I knew her friends at home would help too as they had in the past if ever Mary had needed anything.

They moved Mary back into the ward and the Resident came to tell us the prognosis: the TB was a form that's only known in birds. Mary's sisters and I darted looks at each other. 'Could that be from butcher birds?' I tentatively asked. He was not sure.

The aorta was untreatable. The weak spot would bust at some point – maybe in a few days, maybe weeks. She was going to die. It was just a matter of time.

I gathered the relatives and friends to tell them the news. The niece from London was distraught. She had to leave but wanted to stay. Mary's sister from Melbourne was inconsolable.

Mary asked me to organise for people to be there all the time. She was waking at 3am scared and alone. Why hadn't I thought of that? Each morning early she had asked a nurse to call me and I'd

rushed to the hospital to be with her ... of course she was scared. I contacted everyone and started a roster.

One morning, Mary was dozing as a young enrolled nurse made the bed around her. She was careful and polite.

'She's so lovely isn't she? So cute and sweet.'

'Mary was a nurse you know', I said. 'A 'neurology special' at one point.' Mary had been the nurse helper to all her family over the years, and had a long career in various areas of nursing.

The young girl was so excited. Not just a cute old granny: a woman with skills and talents; a history of work just like hers. Later I heard her telling other young nurses about the amazing old lady in room 2 who had been a 'neurology special'. You shouldn't judge a book by its cover or an old woman by her wrinkles.

The doctor told Mary what was likely to happen to her. And the Social Worker finally came, to check if she had funeral arrangements.

'I'd be a hypocrite if I had a church funeral now' she told me. 'I rejected the church a long time ago.'

Her big brother was visibly disappointed when I told him her decision.

But the very next day, she whispered to me: 'They've all rallied so amazingly, I've decided to let the family have the funeral they want.'

Len was relieved, and immediately called an old family friend who was a Priest.

The next day it was Mary's 83rd birthday, and Moon Watch night. We filled her cubical with balloons, bought champagne, and skyped the Moon Watch gang, so she could see her last full moon rise over the sea.

She died peacefully the next evening, with her niece and sister by her side.

Len organised a great funeral. About 200 people came. It was full of Mary's favourite violin music, lovely photos of her and her friends, and fitting tributes to her radical, rebellious heart, and gentle caring nature. Her family were amazed at the number and range of friends who came, and realised, albeit somewhat late, the life she'd enjoyed on Bribie Island amongst people who saw her as an individual and appreciated her for who she was.

We scattered her ashes in the park under an old man banksia and put a small plaque there, commemorating the Head Luna-Tic – not an insult but a term of endearment from her friends.

FROM THE **INBOX**



20017/03/28 rfenton@supportradicals.org.au

Subject: IS STORY IMPORTANT OR WHAT! Feedback from the SRV theory event this week.

Dear Jane,

I just wanted to say that I thought that the examples at the recent workshop were a highlight and really aided my learning.

many thanks,
Christopher

Hi Christopher,

I appreciate your kind words – thank you. Your comment led me to reflect on the place of ‘story’ in the sorts of efforts we are involved in.

As you might recall, the intents of SRV are to make a difference in the lives of individuals and groups by giving them access to the good things of life, and also to influence how they are perceived. In these ways, SRV is a theory and practice framework for vibrant change in our communities.

Stories can really aid all of our efforts. Four ways come to mind. Firstly, as we hear or read the stories of what has been possible in people’s lives, we can be inspired. Having hope and a sense of what better lives look like can form a huge motivation for change. My observation is that it is not just one story (although sometimes the one story can be a game-changer), but the combination of many stories and many conversations that make a difference.

Secondly, the stories of wounding engage our hearts and minds in ways that can leave us angry, frustrated and deeply disappointed. These stories lead us to look sharply at ourselves and our service systems. They can also be motivators for change. SRV brings a clarity to what we are seeing, through giving us the filters with which to analyse and the words with which to describe the wounds.

Thirdly, stories tend to engage our hearts and minds in ways that shape our mindsets. Hearing a story can affirm values and assumptions that we have held, which can be potent in reassuring us we’re on the

right path. Similarly, stories that are different from our own can challenge our pre-existing ideas and lead us to examine our mindsets. Stories are a gentle way of creating a tension that arises through a challenge to our habitual ways. In this way, it is possible to shine a light on low expectations and other unconscious thoughts and actions. These are crucial steps for positive change in the lives of people with a devalued status.

I am also mindful of the importance of each person with a devalued status discovering their own story. Devaluation takes away from the authentic identity of individuals. Imagine losing your identity as an older person as one mirrors the perceptions of others. Imagine never discovering who you really are because you’ve never had the opportunity to find out and because of limited opportunities and decisions made by others. This is frequently the case for many people with disabilities and mental health issues. Some individuals never discover who they truly are because they have been shaped through the mis-perceptions of others and treated accordingly.

Thank you Christopher for the opportunity to share these reflections, and I encourage you to create more stories and to share them.

warm wishes

Jane

Jane Sherwin is an Accredited Teacher of SRV (Senior Trainer) based in Brisbane, Australia

A CINDERELLA STORY

with thanks to Rosie Olbrycht of Citizen Advocacy South Australia www.citizenadvocacysa.com.au

It is every little girl's fantasy to be a princess, to go to the ball. When I received my invitation I felt like Cinderella and I knew my life would change.

The months leading up to the day were filled with excitement as we planned my dress, hat, bag, hairstyle and makeup. My friend took me to the hairdressers and my hair was styled. I trembled with excitement during the dress fittings, it was wonderful to have something to look forward to. The night before the big day, it took me a long time to get to sleep, it felt like Christmas.

I squealed with excitement as I donned the new dress, and had my makeup done. My carriage arrived and we were off to the castle on top of the hill. As I entered the ball room, music was playing, the room was lit by huge candles and decorated with flowers. I was introduced to the King and Queen for the night and then seated at a table. The food was wonderful and I had wine. I was entertained by minstrels and acrobats and every one at the table laughed and joked.

I was seated with a doctor who didn't ask me whether I had used my bowels, I spoke with a travel agent who told me about all the countries he had visited. Another man at our table was an actor, who told funny stories, and I asked another man, who was an accountant, about taxation. For the first time in my life I felt a sense of belonging, no-one talked about me as if I wasn't there or laughed at me when I spoke.

People seemed interested in me and what I had to say.

All my life I have been told that I have an intellectual disability. And it may be that I learn at a slower rate as it has taken me 75 years to discover that my only disability is natural aging and a lack of opportunity to go to the ball.

This article was written by a Citizen Advocate from the perspective of her protégé of the occasion when the protégé attended her advocate's wedding. The woman in the story had never been to a wedding in her almost seventy years. The last ten years of her life were her best. At her eightieth birthday she was as any other woman of her age ... celebrating over lunch and cake, with many gifts and surrounded by friends and family. Her advocates were her best friends and ensured that life was the best it could be for her even ensuring she was well represented at her funeral. In those last ten years she was loved and became truly herself.

HAIKU TO MY SON MARK

by Wendy McGlynn

Wendy McGlynn is the mother of Mark. She is delighted that Mark is able to pursue roles that he finds satisfying. In particular, Mark is a fisherman and vegetable gardener/provider. Wendy is involved with Foundations Forum, the Sydney-based NSW SRV group.

At the water's edge

A fishing rod in my hand

A fish to be hooked?



The smell of fresh earth

Tomatoes, beetroot and more

My fruitful garden.

Thirty-two thousand, six hundred & forty hours

By Mel Jackman - Mel is Chair of Training and Evaluation for Change, the SRV group in Adelaide, advocate, friend, student, and avid walker.

In May 2016, the Australian national broadcaster (the ABC) news service reported that the new Royal Adelaide Hospital was teaming up with a disability service provider to create 'jobs' for people with disabilities. The chief executive stated 'This is certainly a new skill set for us and it's something we're very excited about,' she said. 'Every day the guys come to work, they go through the city on public transport and they go past the Royal Adelaide Hospital, they actually get to see what they're building.'

In response to this news headline I tried to imagine what it would be like to work at a sheltered workshop. The following fictional story is my response which has been inspired by several people who have taught me to imagine what it is like to be a person with an intellectual disability in this world.

Thirty-two thousand, six hundred and forty hours.

Day in. Day out. For 17 years I have put this bit of plastic into this bit. Creating plastic pegs, buttons, switches and whatever else those able-bodied* people need for their able-bodied lives. Those things that those able-bodied people need that those able-bodied people don't even realise they need. Every time they open those little plastic wrapped knives and forks with that one serviette. I've spent 17 years in repetitive work so they could have that convenience. And every time you turn your light switch on and off. That too is the product of my 17 years of monotonous, meaningless, bland, boring, mind numbing, skill draining, underpaid, meaningless labour.

For 17 years I have worked where there is no chance of promotion. Or even a different

job! I mean, I do get about \$80-\$90 at the end of the two weeks (yes that's two 40 hour weeks). That means I can sometimes get some take-away and maybe even see a movie. That's 48 weeks in a year. For 1,920 hours. A full-time yearly income of less than \$2,500 a year. Maybe if I didn't spend any of my earnings I could go on a short holiday.

For 816 weeks I have spent my life putting this bit into that. Separating that cord from this one. Making the same cut into thousands of pieces of wood for your cheap furniture. Dreaming up a life I will never have. In fact, they call me delusional when I speak of the life I actually might like to have. A job that pays the minimum wage for starters. A family. A home. You see, I'm lucky to have a job ... or so I am told. Back in the day I would have lived in institutions where you get tied to beds, force fed, or not fed at all and given cold baths. They don't know that those things do happen to me. I mean I don't get tied to the bed or force fed. I am lucky. But sometimes I don't get food and I am often scalded when they help me have a bath.

For 32,640 hours I have slaved away. Invisible. Dreaming of a better world. Reminded of how lucky I am to have a job.

You know those swab kits you get at pathology places where they do medical tests? I pack them too. Bit by bit. \$1.25 an hour. That's more than Joel gets though so I should be grateful. You see, Joel isn't as smart as I am. You see, he has behaviours so he gets his own special room and he gets to cut up wires from the computers that I also work on. Dismantling them that is. The wires aren't useful for anything. But it keeps him busy. And he's happy when he gets to buy a

Thirty-two thousand, six hundred & forty eight hours

cont. from page 10

can of coke at the end of his working week. A real treat you see.

Sometimes I have behaviours too. I don't mean to. You see I get so bored. So I get frustrated and I try to speak about it. But I cannot speak. I understand though, but most of them - those able-bodied people who count my bags of knives and forks, or check I haven't messed up the wire buckets and that my cuts are straight enough - they think because I cannot speak that I cannot understand. It's true there is much about what they say or ask me to do that I don't understand. But I understand all too well their anger and frustration at me when I put too many knives and forks in one box because I cannot count past 10 packets. Or when my cut is crooked and they have to throw that bit of wood away. Or when I contaminate the pathology kits because my nose was itchy. I understand those looks of disapproval and exasperated tones. Those eyes rolling and the tense body. And then I get sent to do what I hate the most because I never get that wrong. Those damn switches I put together. Tiny little pieces that I have to bend over for hours at a time putting this bit on this bit. Click. Into the bag. For thirty-two thousand, six hundred and forty hours.

So when I try to speak - well not speak you see because I can't. But when I try to speak to them about what is happening for me I feel something well up slowly inside me. Thirty-two thousand, six hundred and forty hours. That's a long time to be doing almost the same thing. It all comes up and I begin to scream. I might pick something up and throw it because I am being punished for a mistake I didn't mean to make. You see I cannot speak and I cannot understand

why you disapprove of me so much. But I can understand your disapproval and your punishment. And I tried so hard so this makes me mad.

And then I get to stay home for a week until I cooperate again. That's even worse. I stay in my room and sleep because there is not much else to do. There aren't enough workers for me to go out and do things and I have no friends here. So I look forward to work. It is the only other thing other than bed, routine, scalding baths and children's cartoons. So when I try and I fail, I feel bad. And when people ask if I like work I nod 'yes'. It is the only thing I have to wake up to. To spend another 17 years, putting this bit into that. Dreaming of a better world for me.

* 'Able-Bodied' is a term often adopted by sheltered workshops that means 'person without a disability' regardless of physical dis/ability.

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IF you would like to ask about this publication contact Values in Action Association Inc

IF you would like information on the purpose and membership of ANZSG contact ANZSG

IF you would like to find out about SRV matters in a particular state or in New Zealand, contact local groups

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SRV DEFINITION

The pursuit of the good things of life for a party (ie person, group, or class) by the application of empirical knowledge to the shaping of the current or potential social roles – primarily by means of enhancement of the parties' competencies & image – so that these roles are, as much as possible, positively valued in the eyes of the perceivers.