

interaction

VOLUME 28#4 ISSUE 2015



inside:
The Arts
and Disability:
Part II

The Australian Institute on Intellectual and Developmental Disabilities

The Australian Institute on Intellectual and Developmental Disabilities (AIIDD) operates as the information, research and development arm of NCID. The AIIDD is entering into a new and exciting phase that will see it expand its current role of delivering information to people with intellectual disability, their families, service providers and the broader community.

The AIIDD aims to support high level, high quality, independent analysis and strategic policy advice in order to improve the effectiveness of disability service systems, and help sharpen the focus of groups advocating for reform and improvement.

The activities of the AIIDD include:

Publication and Sales

The AIIDD publishes and/or distributes a range of books, monographs and reports relevant to the area of intellectual disability. Sponsorship of the ARTid website: www.artid.org.au

Policy Research Briefs

The purpose of the AIIDD's Policy Research Briefs is to establish what is known and not known about an issue utilising and synthesising extant research, then to define the most productive areas of possible research. Two Briefs currently available are: "Families with Members with Disabilities: Love, Money and Public Policy" and "Individual Funding: Flavour of the Day or Sea Change?"

Training and Consultancy

Training and consultancy services are available from the AIIDD to assist and support people with intellectual disability, their families and support services. Training and consultancy services currently available include:

- Family Skill Development
- Advocacy Skills and Self Advocacy Skills Development
- Inclusive Schooling Strategies

Roundtables

The AIIDD aims to provide high-level forums where research is discussed and debated with the aim of proposing policy principles and program directions, furthering the research agenda and fostering new partnerships between participants.

Research and Development

The AIIDD aims to commission evidence-based research independent of the political agenda, that will advance the discussions, debate and ultimately the policies affecting Australians with intellectual disability and their families. Key priority areas include unmet needs, accommodation support, employment, inclusive education, family skills development and leadership.

iNSIDE

Editorial	4-6
The Power of Creativity	7-16
<i>- by Dulcie Stone</i>	
How Sickness Changes Your Life	17-19
<i>- by Tim Steenson</i>	
Through a Different Lens — <i>On Beauty, The Film</i>	20-21
<i>- by Veronica Wain</i>	
Imagine ID	22-23
<i>- Advertisement</i>	
Our Voice — <i>Loud and Clear</i> begins in Queensland	24-25
<i>- by Veronica Wain</i>	
The Gift of One...	26-33
<i>—by Camilla Downs</i>	

Regular Feature

My Word!	34-35
<i>- by Christine Regan</i>	

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i Editorial

Creativity in action: the essence of healthy lives and welcoming communities

"It is in the act of creativity that empowerment lies, and through sharing creativity that understanding and social inclusiveness are promoted."

Francois Matarasso

Interaction, the Arts and Disability, Part II continues on from our previous volume in showcasing innovation and creativity within the world of intellectual disability. This diverse community, historically sidelined due to a lack of acknowledgement and understanding, hidden from sight or held up as spectacle for not altogether the "right" reasons, is rich with talent and hungry to be seen and heard. Vibrant, authentic, real — these are words that come to mind when I reflect upon my engagements with the many individuals I have come to know and work alongside over these past 20 years.

The featured articles in this issue are penned by two gifted women, one from Australia and one from the United States, at distinctly different stages of life, reflecting the tremendous accomplishments of the past and the continuing challenges we face today.

Dulcie Stone, a pioneer of creativity and innovation in engaging people with intellectual disability and the arts in Australia, shares some powerful examples of *becoming* in her contribution, "The Power of Creativity". Treating readers to some insightful and inspirational stories of people who have been fortunate to have crossed her path during her long and eventful career supporting people with disability, Dulcie takes us on a journey as she, with the support of others, was able to facilitate the discovery of hidden talent and ability laying within those precious souls lost in systems lacking insight and flexibility. These stories demonstrate what can be achieved when creativity, passion, patience and a will to understand and make a difference are harnessed with an intent to help another reach his or her potential. The article is but a "taste" of Dulcie's forthcoming book, "Changing Lives, Changing Times" and we are honoured to have her open this issue.

The second featured article has been contributed by Camilla Downs. Camilla wears many hats, but none so proudly as Mother to Lillian and Thomas. Lillian was born in 2001 with a genetic difference located on the 18th Chromosome. This rare condition affects around 1 in 50,000 — the condition does not have a "name" as such, but is simply called 18p- or 18p deletion. Camilla and her two children reside in Reno, Nevada. She is a best-selling author and shares some of the family's story and

personal insights about their lives together and the creative ways she chooses to construct her and her family's lives.

Gifted public speaker, Tim Steenson was also born with a similar genetic difference located on the 18th Chromosome and has personality plus when it comes to constructing a good story coupled with his witty delivery. Tim is thirty-nine years old and lives in Newcastle with his Mother, Mary, who is undoubtedly one of his greatest supporters. Tim shares a speech he wrote and presented to his local Toastmasters Group in the first instance and subsequently presented it at the Chromosome 18 Australasian Conference in Sydney in 2012. I invited Tim to share his speech for many reasons, not the least of which is his obvious gift in being able to tell a story involving great challenges with a sense of wry humour and dry wit.

With Lillian and Tim's stories of living creatively with rare chromosomal conditions, we have showcased the UK-based IMAGINE research project in this issue. The project is investigating the link between genes and patterns of behaviour. Please take the time to peruse the article and consider becoming involved or forwarding the information to someone you know who meets the criteria.

Another project of a different kind is also showcased and concerns the work of fashion photographer, Rick Guidotti. *On Beauty*, a new film released this year in the United States is another exploration of notions of beauty, stigma and acceptance. *On Beauty* tracks Rick's work in his quest to challenge notions of beauty across the globe. His work spans some 15 years and has seen him develop innovative programs and work within education and medical environments in his endeavours to reframe how we see one another, in particular those born with genetic difference. "Change how you see, see how you change" is his mantra and the film brings insight into his practice and those whose lives he has touched.

Advocacy and self-advocacy are indeed creative endeavours when we reflect upon how far we have come as a global community, seeking to be heard and forging new pathways to create good lives of our own volition. Closer to home, a new, emerging self-advocacy group has begun to take shape. They are "Loud & Clear". The new group, supported by Sunshine Coast based Disability Service Organisations, Parent to Parent and Spiral have now convened several foundation building gatherings and have recently elected their Our Voice State Representative, Kate-Lyn Mackenzie who will attend her first conference in Adelaide in November. The group are the first Queensland Branch of Our Voice and are mentored by Spiral's Kathy Walker as they embark on a new phase of their lives in becoming self-advocates.

Creativity permeates every facet of our lives, finding expression in a myriad of ways. From the gifted writer who finds release in the written word, to those who express themselves via visual and performing arts and the many other guises that art and self-expression intersect, the personal stories in this issue bring possibilities for each of us to consider. My hope is that for those who are yet to find their own avenues for

expression are inspired to explore new pathways and that each of us is reminded that the everyday, moment to moment, day to day are opportunities to be creative in how we approach that which is presented before us.

Dr. Veronica Wain, PhD
Editor



Veronica Wain is an academic, filmmaker and mother of three. Her youngest daughter, Allycia, now twenty years old, was born with a rare deletion located on the 18th Chromosome. Veronica is a board member with Inclusion Australia and Parent to Parent Assoc Qld Inc and serves as a committee member with Chromosome 18 Australasia. She has a particular interest in the creative industries, social justice, advocacy and intellectual disability. Veronica is currently working with Equity Works Assoc Inc as State Coordinator for a Queensland Government-funded pilot program, Respite Plus and is President of

The Sunshine Troupe Inc, a performing arts collective for people with intellectual disability. Veronica has presented at conferences nationally and internationally and has just recently been invited to present at the 2nd Interdisciplinary Net Global Conference on Empathy at Oxford, later this year.

NOTICES:

Wings Away: Norma and Harry Rigby Scholarship

At the centre of this issue is a copy of the application form for the above Scholarship. This can be removed and used to apply. Alternatively, to receive a colour brochure, please contact Guna Adens on 02 6296 4400 or guna.adens@ncid.org.au

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Would you like to receive one year's free e-subscription for having a Letter to the Editor published in *Interaction*? If so, we would love to hear from you – your opinions/thoughts are much valued by us.

Alternatively, you may like to send us an article telling us about your experiences as a person with disability, as a family member or organisation. The author of any such articles published in *Interaction* will also receive one year's free e-subscription.

We look forward to hearing from you!

Email: aiidd@aiidd.org.au

The power of creativity

Dulcie Stone

A 1980 report from the International League of Societies for the Mentally Handicapped to UNESCO states:

'Arts centers and arts programs are dedicated to the idea that each person, no matter how handicapped, has a unique vision, and that everyone should have the opportunity to express his or her individuality and creativity through the art experience.'

Although I'd been managing creativity-based programs since the 1960s, full comprehension of the fundamental part creativity plays in all our lives took many years. The history of that journey was published in 2002 under the title of 'Switching on the Light' (Promoting Emotional Maturity). Below are some factual cases and true stories (not real names):

Penny's Story

In the late 1960s, the Mildura Council's social worker was asked for help by the mother of three year old Penny Evans. Penny had just been expelled from kindergarten for disruptive behaviour. She also climbed unclimbable fences, roamed unsafe streets, slept little, was hyperactive, naughty, cheeky, and flaunted a vocabulary which would do credit to a wharfie. Mrs Evans was seriously worried that her daughter was headed for an accident or worse. Worse again was Mrs Evans' fear that she would hurt Penny herself.

The social worker phoned me, as Principal of the W.J. Christie Day Training Centre, asking to enrol Penny in the Centre. How could we? Penny didn't have an intellectual disability.

Eventually persuaded that the situation was extremely critical, we agreed to mind Penny one morning each week until more appropriate relief could be found.

Penny was demanding. In addition to her talent for swearing, her mastery of language equalled that of a precocious ten year old. She never stopped talking, questioning, arguing, thinking out loud. She never stopped moving. She never stopped pressuring her minders into finding new interests for her. She learned quickly. Whatever was the go, Penny got on with it.

Because our minding morning had been arranged for a time when few students were present, we were able to spend intensive hours with her. She blossomed. This mischievous troublesome challenging child kept us on our toes. Keeping one step ahead, we planned new and stimulating tasks and activities. We were taking a great risk. If the authorities learned what we were doing the Centre could lose the little Government funding it did receive.

But we had a strong ally. Dr Dennis Maginn was our visiting psychiatrist. Highly respected by committee members, parents, students, and teachers his support in those very stressful times was invaluable. He showed a compassion, a patience and a

flexibility that was in those days very rare. On his next regular visit, I told him of the arrangement we'd come to with Penny's mother. It needs to be understood that I would not have told any of the other visiting experts.

After interviewing Penny and her mother, Dr Maginn said: 'Enrol her officially. If you don't help her, who will?'

Penny was enrolled full time, with a personal program tailored to her special needs: academics with the teenagers, creativity-based activities with the adults, and play with the young children – with a stern warning not to swear.

To follow this complicated schedule Penny was given her own printed program. Each morning, after consulting her personal timetable, she took herself to the different designated areas. To do this she was given her own clock, a pretty ornament with a flower-faced dial.

Penny understood that the program had been devised especially for her. When she moved from place to place, she went alone. No one took her hand. No one monitored the time. Daily, Penny danced through her program and revelled – often very loudly – in the new knowledge she was acquiring.

This toddler would often present herself at my office door, lean against the doorjamb and announce: 'I feel like a little chat.' She'd perch on a chair at my side, and we'd have our little chat about whatever was in her fertile mind. When the little chat was over, she'd climb down from the chair and trot off to her next class.

In due course Penny was given the assessment she should have had much earlier. As expected, she proved to be of well above average intelligence.

The 'naughtiness', which had exhausted everyone but Penny, had been the result of boredom. That quick mind demanded stimulation, and the world she'd been born into had not known how to satisfy it.

So why had highly intelligent Penny blossomed in this segregated place geared to the needs of the well below average in intelligence?

Because this place, unlike so many of its day, was facilitating an environment in which each person was stimulated to learn and to grow without pressure.

To do this, regardless of the degree of intellectual capability, each person was able to feel equally important, equally free to explore, to choose, to accept responsibility, to be their own distinctive self – whatever that SELF truly was. And, further, to therefore learn to exercise SELF-discipline and to grow in SELF-discipline.

Only in this segregated world we had opened for her, had Penny found the flexibility, the patience, the empathy and the vital stimulation she needed in order to blossom into her still exhausting, but beautiful, self.

This was the road Penny's small feet had been set on – the road to self-knowledge, self appreciation, self-discipline.

There came the day she had to leave. Segregation was undesirable for all our people, but most particularly for Penny. Yet, as part of the moving on, it was important that she should understand why she had been here.

How to set the record straight?

Penny was bright. With Mum's permission, five-year-old Penny was told just how bright she really was. She was told that she'd been sent here with people who were not so bright so she could learn, that here she'd learned things kindergartens didn't teach - reading and writing and making mosaics and colourful candles. She was told that now she was ready to go to a mainstream school where she'd learn more and more things she wanted to know.

What she was too young to understand (I think!) was that she'd also learned to cope, to get a clear picture of her own worth and her own potential, and that this had taught her to be ready to move on to the disciplined programs of the mainstream schools. She eventually went on to tertiary education and graduated in a 'helping profession'.

Reports came through to us that her defence of handicapped people was ferocious. As young as eight years of age, she berated a busload of adult queue jumpers for pushing aside a wheel-chaired passenger. 'That's not how you treat them! I used to go to school with people like that! You have to be nice to them!'

Penny's story encapsulates what the Centre was doing, and why we received such strong opposition. Not only were we teaching the 3Rs which was at that time forbidden, we were encouraging freedom of self-expression through the arts.

As for Penny, so for everyone. Pride in self. Knowledge of self. Development to the fullest potential of the self. This is the lesson Penny teaches. Each person is different, each may require totally different management.

In our segregated world, Penny had found the flexibility, the acceptance, the empathy, and the vital stimulation she needed.

Lucky Penny. Without Dr Maginn she'd have been in real trouble. His strong support of the controversial program had saved Penny from a very dark future.

Reni's Story

Reni was a beautiful sixteen-year-old with an elfin figure, long dark curls, and enormous brown eyes. She and her large family had migrated to Australia when she was in her early teens. Because she'd been born with one leg significantly shorter than the other, she'd never been to school. Reared in a culture which rejected people with disability, Reni was deemed to be not worth educating. Not worth anything.

At sixteen, she could DO nothing. An obedient little shadow, she couldn't sew, knit, help in the house, cook or read. She didn't even know how to play – probably because she'd been isolated from other children.

When her father died, someone had the bright idea that her mother would get a rest from Reni if she came to us. We were supposed to mind this teenager, nothing more. Again, not unusual.

Once in the Centre, Reni saw people other than her family. She saw them DO things – read, write, draw, play, dance, sing. Yet some of these people also had disabilities. Some were even in wheelchairs.

Not surprisingly, Reni was a very unhappy young woman. All her life she'd been surrounded by 'useful' people. All her life she'd been told she was useless. Bad enough. Plus now, here were these new people, some also physically disabled, doing wonderful things. It cruelly reaffirmed what her family had always told her. She was truly useless. She was not worth anything.

So now each day when Reni limped through the passageways into her classroom she began to change. The obedient little shadow her family had reared quickly became a destructive monster.

Whatever her new companions did DO – an academic assignment, a painting, an article of craftwork – Reni tried to destroy.

Somehow, no matter what her desperate teachers did to keep her from them, she managed to find scissors or knife. Unless stopped in time, she slashed everything the others made.

At last Reni had found something she could DO. She could destroy.

Although slashed students' work was distressing, for her teachers the more pressing problem was: When will she try to slash the students?

The place was in uproar.

Would Reni have to go?

Not just yet.

By the time of Reni's enrolment, Centre numbers had grown to over 60 students and 12 teachers, as well as ancillary staff and volunteers.

We talked about Reni, thought about Reni, agonised over Reni's plight.

She was lucky. Not only had her teachers seen others like her before, so had her fellow students. In fact, a number of them had themselves recovered from the same terrifying despair as Reni. With empathy and compassion, everyone went that step further which was to rescue Reni from her private nightmare.

Excused from all programs, both formal and informal, her freedom was heralded with the present of a large box of coloured chalks and the use of the huge empty blackboard. The teacher made it clear: Reni could do whatever she wanted to do. She need follow no timetable and no structure. She was expected to be nowhere at any specific time and to do nothing at any specific time. Meanwhile, here was this opportunity. Empty board. Coloured chalks. No rules.

Reni took full advantage of the opportunity. While the other students followed the usual program, she spent all her Centre time drawing multicoloured meaningless scrawls on the blackboard. Everyone admired them. The 'meaningless scrawls' made colourful pictures. They were, indeed, beautiful. More admiration, lots of attention.

Gradually, she progressed to simple recognisable drawings. Gradually, she left the board to participate in the craft, art, music and dancing activities of her fellows; later broadening to academic achievement.

In an amazingly brief span of time, Reni matured into a wonderfully warm, fun-loving teenager who did not need to destroy. Reni embraced her chance to be

positively creative, and the destructive monster blossomed into a delightful angel who bubbled with enthusiasm and joy of life.

The highlight is on video. Reni is performing with her many friends (students and teachers) at a public concert. The dark curls are swinging, the brown eyes dancing, the smile a mile wide.

So we gave the attention. We accepted the outrageous behaviour for what it was: a cry for help – a scream of despair – a plea for attention. And we gave the attention.

Dale's Story

In the late 1990s, as Coordinator of the Adult Literacy Program at the Upper Yarra Neighbourhood House, I was asked to implement a weekly program for a group of men with intellectual disability. Recently released from an institution and now living in outer suburban group homes, their carers would drive them out to us. One of the men was Dale.

Grey and gaunt, Dale typified the institution image that is probably one of the most heart-breaking sights you would ever see. Born with intellectual disability, he was a very gentle and courteous man of about fifty with handsome even features, tall sparse frame and keen blue eyes.

He never laughed, or even smiled. Those alert blue eyes were wary, sad, interested – all at once. He seemed to be taking in everything without taking part in anything. He didn't know how to make a choice, of any kind. Asked to make even the simplest choice 'Do you want tea or coffee?', he deferred to his carer who reluctantly answered for him.

He could initiate nothing for himself. Asked 'Do you want to do this? Or that?', he deferred to his carer who tried without success to get an answer. Dale lived with fear. He was fear, the embodiment of fear. An aura of fear surrounded his grey person and penetrated clear through to his soul. Until gradually, slowly, the atmosphere of fun and freedom and achievement and goodwill of the creativity-based program wrought its magic and – one day – Dale smiled.

It was a celebration. We tramped into the next-door cafe where most of the Friday-group lunched, and celebrated. Dale came too. He ate a huge gourmet meal, and beamed.

I drank my coffee, smelled the warm country smells of steaming soup and hot pastries and leather and wool, and watched the fine rain drip down the lacy windows – and watched Dale with the group. And I beamed.

That Upper Yarra cafe and its place in our innovative program was significant. The lunchtime exodus from our rooms had evolved over a period of time. Starting with a couple of tutors or committee members looking for a quiet place to talk, it grew to a take-over of the back restaurant section. While take-away customers queued at the front counters for the delicious food, our people sat at the tables and talked and ate and talked and ate – and drank coffee.

What was happening in this cafe is very important. The queues at the front counters were locals on lunch breaks – shop assistants, clerks, tradespeople, housewives,

labourers, farmers..... These isolated locals had seen few, if any, people with intellectual disability. Their reaction was overwhelming acceptance and support.

The reaction of the owners and staff of the café was the same. Once, when Dale was absent, they were concerned in a personally caring way: 'Is he sick?' 'Give him our love'. Once, when there was a communication breakdown, the café people made phone calls and monitored messages to sort it out. When our people ordered lunches in speech that was almost inaudible or difficult to understand, the staff were, without exception, caring and patient yet never condescending. They did not talk 'down', they talked 'with'.

In this unexpected place, the unexpected was happening: Total inclusion of people with intellectual disability into a community; total acceptance – caring, concerned, respectful and thoughtful acceptance.

Katy's Story

In the 1996 publication 'Creative Writing for People with Intellectual Disability', Katy Slade, using a scribe, wrote: *'Creative writing is important because it gives people more chance to explain. And it helps people. Language is important. People – if they're not normal and not very bright – should be given time. People might feel defensive sometimes. Teachers forget we can get around it sometimes.'*

If this was how Katy felt, what about others? Knowing she had an intellectual disability, Katy was able to talk about it. A young woman in her late twenties, she was a 'word' person. She was also a philosopher. She loved talking and thinking and communicating through words. But talking reached a comparatively small audience.

For Katy, writing was more than merely a means of self-expression. Writing gave her a chance to communicate to a wide audience. So that interweaving within the one exercise was the therapeutic activity of self-expression, together with the intense satisfaction of knowing her important thoughts were reaching many unseen readers.

Given this unique opportunity to have her ideas and ideals expressed in the written word, Katy, whose actual reading and writing skills were extremely limited, delighted in describing herself as a writer. And so she should.

Sadly, Katy died before she reached thirty. But her thoughts are still reaching others.

Pete's Story

In the 2000s, I was working in mainstream schools as a teacher of creative writing and also as a special assistant for children with a disability. When working with Pete, the two roles combined.

Pete is one of the most fascinating children I've ever met. Not labelled as requiring special needs funding, he actually did have a significant learning difficulty. For reasons not satisfactorily assessed, reading and spelling were always going to be difficult for him. However, Pete has rare talents. His problem was that they didn't fit into any school curriculum.

Although he was only ten years old when we started working together, he had an adult wit, an adult mastery of the spoken language, an exquisite sense of humour, an

ability to think very quickly and a superior memory for stories. Pete could recite the entire story of a full-length movie without even – well, almost – pausing for breath. And then immediately follow it with another – ad infinitum. He could talk very very fast – another talent he took great pride in.

The question was how to preserve this wonderful personality and, because of academic inadequacies, prevent deterioration into low-self esteem and eventual negativity. Given his superior gifts and significant deficits, ten-year-old Pete was one of those delightfully different, challenging, troublesome, intriguing children who had arrived at an unusually critical crossroad. His future could go either way – impressively ‘good’ or dangerously ‘bad.’

Step one was, as always, getting to know each other.

The stories Pete told, which I scribed in order to free his creative genius from the restrictions associated with writing and spelling, were almost exclusively tales of violence. Pete took endless delight in relating particularly gory stories. Pete’s teachers were appropriately horrified, which of course suited him just fine. I was mildly alarmed but, as obedient scribe and experienced veteran, neutrally non-judgmental, working to establish the trust needed to move forward.

In due course, as he begins yet another gory tale, I call a halt.

Setting down the pen, I say ‘Stop right there, Pete’, and set the pen aside.

Surprised, he stops dictating. ‘What’s wrong?’

‘That’s enough,’ I answer. ‘No more violence.’

He blinks, says: ‘Okay’, then gives me back the pen.

Bracing myself for dispute on the topic of violence, and prepared to again set the pen aside, I ask: ‘What do you want me to write?’

‘We’re doing a new story,’ he happily dictates. ‘Are you ready? It’s called “Who Stole the Shark’s Teeth”?’

As quick as that. Out it flowed, a funny, witty, mystery story – plus eventually great cartoons. It was a new road and Pete had begun a new journey, which he seemed to be thoroughly enjoying. Fingers crossed!

He began to refine and polish his notable skill of inventing imaginative stories. When each story was finished, he copied my writing, a task which by a kind of osmosis subtly improved his spelling and reading. Eventually, he sometimes worked for a whole hour without saying a single word!

His books were distinctively typically Pete. The copied words were illustrated with skilful, brightly-coloured, cartoon-type drawings. If he made an error, he was not a mite disturbed. He didn’t attempt to correct it, or to erase it. He merely found some way to disguise it. Thus for example, a word incorrectly copied would be quickly covered with some kind of quirky illustration that exactly fitted the size of the mistake; a drawing he perceived as unsatisfactory would be speedily adjusted to camouflage the ‘error’. Erasers were not to be considered – probably because he thought the time taken to use them might derail his quick brain from where it was heading.

The humour, wit, inventiveness and style of the high-quality drawings and intriguing stories were uniquely his. Pete was quick to understand this. If low self-esteem ever tried to rear its destructive head, it was going to have a fight on its hands.

There's a Pete story which is sheer joy, and gives some insight into how we built our bridges of trust and enjoyment in each other:

It's early days. Pete's still trying me out. He comes in with a pack of cards, plonks them on the table and announces: 'Okay, Dulcie. Today we play Snap.'

'Okay, Pete,' I answer. 'After we've done our work.'

That's okay by Pete who's always polite, always happy to negotiate.

Twenty minutes after intense 3Rs work, he brings out the pack of cards and carefully divides them into two precisely equal piles. We start to play. It's a clash of goals and abilities. Pete, who is intensely competitive, needs to win; except he's markedly short on concentration. I couldn't care less who wins; my concentration can be excellent. So, although I should beat him hands down, my usual ability to concentrate is zero because I don't need to win.

Result – I lose. My stack of cards dwindles, his is a mountain.

Pete, having frequently heard me say, 'Concentrate, Pete', turns the tables and patiently sighs: 'Dulcie! You have to concentrate. Here ... take these.' Generously, he restores the packs to exactly equal levels.

Again I'm losing, he's winning. Again he exhorts me to concentrate, and generously gives me another chance to win.

And again I lose.

And again.

Finally, he dramatically sighs. 'Dulcie! I tell you what. You've been good to me. So I'll give you a present...'

Wait.

Very serious, Pete says: 'I'll stop cheating.'

Goggle-eyed, I watch Pete withdraw the two Jacks he'd hidden in his sleeve. The best student present I've ever had.

Pete's hyperactive moments were something to behold. Fast-talking, fast-moving, funny, witty, singing, dancing, relating jokes at high speed, he seemed at times incapable of sitting still – until he became engrossed in his creative project of the moment. Initially the times of concentration were brief, then he'd be off again. That was when we were alone. When others were in the room, forget it. Keeping still was absolutely impossible. He loved to shock, to overawe, to outwit, to hold the floor.

Gradually, in the next few months, growing maturity became marvellously evident in his increasing ability to exercise self-control.

A little over a year later:

Pete's working in a group. He's been head down and shoulders hunched totally rapt in his book-cover illustration. That was yesterday. Today, working in the small group, he announces: 'Okay, Dulcie. Please get your pen out. We're ready to go on with the story.'

Following our proven pattern, Pete dictates, I scribe, and another wonderfully imaginative story is well under way. Except – Pete's kneeling on his chair, rocking up

a storm. Not showing off, or attempting to shock his friends, as he would have done a year ago, but hyperactively in high gear.

I put down the pen. 'You'll have to stop rocking. You can't concentrate well enough like that.'

'I can't help it.' He rocks on.

But this year, Pete's already shown himself to be impressively more mature. Though concentration has previously been suggested, it's never been a non-negotiable order; a distinction Pete will surely comprehend.

So, for the first time ever, I'm tough on this point. 'Well, you'd better help it,' I declare. 'Self-control, Pete.'

He eye-balls me with those wonderfully candid eyes; his quick mind is assessing what I've said and how I've said it.

Then, he sits down and gravely answers, 'You're right.'

Half an hour later, with no further evidence of hyperactivity, the story is scribed and Pete is diligently preparing to copy it into his hand-made book – concentrating intensely. That spelling has to be correct.

Eventually our partnership developed to the point where we were discussing how he would manage in secondary school. I later learned that he was coping well. He was being nurtured by understanding teachers and happily supported by his close friends who'd always valued him for who he is. He was not teased, ridiculed, ostracised or bullied.

In 2014, his friend, a former creative writing student who is now a highly respected TV journalist, reported that Pete now manages his own building business.

Too often, people like Pete are not given the chance – too often with dire consequences.

Criminology, Creative Arts and Education

In 2004, the Massachusetts program titled 'Changing Lives Through Literature' received the New England Board of Higher Education Award for Excellence and an Exemplary Education Grant from the National Endowment for the Humanities.

Initiated in 1991 by Massachusetts University English Professor Robert Waxler and Judge Robert Kane, the program is designed for criminals sentenced to read and discuss assigned books as an alternative to imprisonment. The program's aim is **to facilitate self-exploration and increase the ability to confidently communicate ideas and express feelings.**

The creativity-based program endorsed by Dr Dennis Maginn has exactly the same aim. Without his official approval, Pete and many others might not have been given the chance to grow through positive creative experiences.

Without Dr Maginn's encouragement and support, I would not have received the following email: *'We are investigating a community cultural development model, engaging professional community artists (as opposed to therapeutic models) in cross disciplinary research between Criminology, Creative arts and Education. I can see*

that you have been a pioneer in this area for some time. Alas it is a long hard battle we have to convince the bureaucrats of what we know.'

Kiersten Coulter

Department of Criminology

University of Melbourne

February 27, 2003



Dulcie's teaching and administration experience includes: 24 years as Principal of the Mildura Day Training Centre for children and adults with intellectual disability; teaching children and adults with physical, psychological and psychiatric impairment; teaching in kindergarten, mainstream primary and secondary schools, and adult education; teaching gifted children; and 16 years honorary probation officer, educational consultant and lecturer.

Writing: Fiction and non fiction books and stories; Articles and Poetry.

1981: Awarded MBE for 'service to the handicapped'.

1996-97 International Biographical Centre Award: 'Woman of the Year.'

NOTE: This year, Spectrum Publications is publishing Dulcie's new book '**CHANGING LIVES, CHANGING TIMES**' which updates and expands 'Switching on the Light'. The book is dedicated to the late Dr. Dennis Maginn, former Director of the Victorian Mental Health Authority. *[Further details will be advertised in the next issue of **Interaction**.]*

HOW SICKNESS CHANGES YOUR LIFE

Tim Steenson

[A transcript of a speech Tim presented as a member of Toastmasters and as a speaker at the Australasian Chromosome 18 Conference, NSW]

TERRIBLE NEWS — MUM HAS CANCER!

YES ! MY MOTHER HAS CANCER AND BOY HAS MY LIFE CHANGED.

First there is the news. You have cancer.

Is my Mum going to live or not?
The phone never stops ringing. All she talks about is how long she has to live.

Is this changing my life? Yes.

I had a comfortable life with a caring person looking after me. Feeding me, cleaning the house, doing my washing, driving me places, basically doing everything for me. I depend on this person. What will I do if she dies? My life will never be the same. We both get very unhappy and angry at each other. Until things settle down.

Then there is the trip to hospital.

Great, I get to heat up my meals, do the washing, put out the rubbish, visit at the hospital and find my own way around without my driver/Mum.

Mum finally comes home from hospital. But she is still not completely well. So I have to keep putting out the rubbish, heating up my meals and keeping the house tidy. Now I also have to make millions of cups of tea and answer the phone and the door with people wanting to know how Mum is.

Then, while she is still recovering, she has a special birthday party making lots of work for all of us.

Women!

VISITING PERTH WESTERN AUSTRALIA

After this, she takes us to Perth for my brother's wedding. She wasn't going to miss that! She travelled on the plane with tubes coming out of her.

IT WAS FUNNY going through security. When they said "Madam, can you put the bag through security?", Mum said "No, it is attached!". Not as bad as when she took a knife through international security on her way to L.A. (BUT THAT'S ANOTHER STORY).

We arrive in Perth and Mum drags me to Margaret River so she can taste wine. We then attend my brother's wedding. So she is now happy.

She then drags me around Perth visiting Kings Park and Cottesloe Beach. She took millions of photos of the sunset because it was on the West Coast — the opposite coast to what we have.

When we get back from Perth, Mum has to have Chemotherapy — every 3rd Friday. The Chemotherapy at first doesn't make Mum too sick. But the last lot made her very sick and she had sore LEGS. She doesn't want to have it again. But she has two more to have and they will make her very sick again.

My brothers and sister have no idea what it is like to be here all the time. They only saw Mum with her wig on, when she was out and about. I hardly saw her with her wig on as she took it off when she walked in the door.

I saw weird little hats or a bald head.

She never tells my brothers or sister when she is sick. She rings them when she is better so they don't worry.

My day starts, I get up and watch some TV and when my Mum wakes I make her a cup of tea. If she is sick she stays in bed for a while. If she was well she went to work. Some days when she was home sick, I wished she was at work. All I hear is: "Tim, can you get this?; Tim, can you get that?; Tim, can you bring in the mail?; Tim, are there any emails?; Tim, can you answer the phone?; Tim, have you put on the dishwasher?; Tim, have you unloaded the dishwasher?; Tim, have you brought in the washing?"

No Alzheimer's yet. She still remembers my name. On the days she goes to work. I can relax and go out if I want to.

Everyone worries about her and ask me all the time how she is. She won't ask for help because she likes to do everything herself. Unless it was: Tim put out the rubbish, Tim bring in the washing, Tim has the postman been?

How did I get to be so lucky?

I now spend my whole life putting the toilet seat down. On Chemo, she had to drink lots and so she was forever going to the toilet. So the toilet seat was always down. Just in case, I would run and check when I saw her heading that way.

This has all been very strange for me as I actually see my Mother sitting down a lot these days. She never used to stop working.

Boy my life has changed!

I do love my Mum and would do anything for her. I hope that what I am doing is helping her and I do hope she lives a long, long time. She is planning 20 years.



Wings Away

Norma and Harry Rigby Scholarship

*Celebrating children with disability
and those who work with them*



Terms and Conditions of Scholarship

Two (2) scholarships of up to \$1,500 each will be offered each year to assist with attendance at a conference at which the successful applicants will be making a presentation.

- ★ One to an employee of a charity supported by a State/
Territory Wings Away Association
- ★ One to a student undertaking postgraduate study that will
directly benefit children with disability

The scholarship will be awarded to the employee and student who can demonstrate the greatest benefit to children with disability.

Evidence may include examples of undergraduate work, reference(s) from employers, lecturers and/or course supervisors and history of work with children with disability.



How to apply

Go to wingsaway.aiidd.org.au/scholarship
and
Fill out the online form

Applications can be made at any time

Closing Date: 31st December each year with successful applicants notified by 1st March the following year

If you have any difficulties filling out the form or need assistance,
please contact 02 6296 4400.

Proudly supported by

Australian Institute on Intellectual and Development Disabilities (AIIDD)
and
National Council on Intellectual Disability (NCID)

w: aiidd.org.au

t: 02 6296 4400

WINGS AWAY

NORMA & HARRY RIGBY

SCHOLARSHIP

Wings Away : Wings Away is an association of ex-TAA Air Hostesses, Australian Airlines and Qantas Flight Attendants founded in 1966 by Elaine Swain (Smith). Elaine's original vision was for all States to support a single national charity. However, each State wished to choose their own charity to support. It was 10 years before her dream of a National Charity came to fruition. At the 1976 Presidents' Conference, members agreed to support an embryo library being built to help parents of children with disability. The Wings Away Collection is housed at Charles Sturt University. Since the start in 1976, Wings Away has raised almost \$105,000.

Norma Rigby: Norma was the first Executive Officer of the Australian Association for the Mentally Retarded (AAMR) – now known as the National Council on Intellectual Disability. For some time, she had dreams of a Lending Library to help parents of children with disability, but no idea where the funds would come from.

A solution came in 1974 when Faye Jamieson (President, Wings Away, SA) contacted Norma at the suggestion of Ansett Capt. Colin Watt (who was involved with AAMR) and asked her how Wings Away could assist in any project. The outcome was that, at the 1976 Presidents' Conference, it was agreed to set up a National Charity and \$1,000 was the first amount donated to Norma's slowly growing library. The 1978 Conference voted unanimously to support the Library for the next two years and the amount of \$1,438 was donated and a Building Society Account was opened in the name of 'N. Rigby AAMR Wings Away Library Fund'.

At the 1981 Conference, Norma accepted the position of National Patron and so began a 25-year association with a lady who was not only interested in what Wings Away was doing but who had as many dreams as Elaine Swain.

In addition to the generous yearly donations contributed by each State, Wings Away has contributed large amounts to the Library and its projects on three occasions: in 1992, Queensland contributed \$3,000 to publish the book 'Public Policy – Private Lives'; NSW Wings Away donated \$3,000; and the proceeds of the DC3 flights at the 2006 Reunion and Conference in Melbourne will be go to the 'Norma and Harry Rigby Scholarship'.

Norma's work with Wings Away was generously supported and encouraged by her husband, Harry.

Well, you might think **THAT** was bad!.....

She has now retired and is driving me nuts.

I put down a glass and it disappears.

"Mum, where is my glass?" — "It's in the dishwasher";.

"Mum, where's my papers that were on the table?" — "I put them away".

"Mum, I am going to bed".

"Mum, where are my pyjamas?" — "They are in the wash".

I am not going to last 20 years!!!

Tim resides in Newcastle with his Mother, Mary and has been an active Toastmasters' Member for many years. He is a member of the Chromosome 18 Registry and Research Society, Australasia Committee. Tim has a keen interest in Rugby League.



Tim with Paul Harragan at 'The Footy Show'



Tim and his mother

Through a Different Lens – *On Beauty*, The Film

Veronica Wain

On Beauty is a new film garnering significant attention in the film world, boasting festival awards, including Best Documentary Short at the 2015 Geneva and Cleveland International Film Festivals. Released by Kartemquin Productions and directed by award-winning filmmaker, Joanna Rudnick, the film spans five years, documenting the work of Fashion Photographer, Rick Guidotti.

Rick has travelled the globe since 1998 in his quest to challenge our perceptions about physical beauty and how we see one another. His career as an accomplished fashion photographer took a turn towards a different path on the day he glimpsed a young woman with the rare condition, Albinism. Since then, Rick has championed those whose physicality sits outside a standardised definition of what “normal” and “beautiful” might look like and founded his not-for-profit organisation, Positive Exposure.

On Beauty focuses on the stories of two young women affected by two different conditions, exploring their journeys alongside Rick. Born with Sturge-Weber syndrome, Sarah was subjected to cruel bullying in the eighth grade and retreated to home schooling. Meeting Rick changed her life. Jayne lives in Eastern Africa and was raised by her grandmother after she was abandoned by her mother. Jayne was born with Albinism and her story is remarkable, seeing her emerge as a community leader in spite of the stigma that the condition carries within her culture. The film illustrates how perceptions of ‘self’ can be changed when another sees us differently, unlocking the hidden potential that resides within us all.

Since the film’s release in the festival circuit, Rick has continued presenting his work and delivering lectures across the United States and beyond. His latest project is FRAME – Faces Redefining the Art of Medical Education. This web-based educational library has been created to reframe how information about genetic conditions is presented to health professionals, families and the wider community. Rather than focussing on the condition and person as “specimen”, the short films on the website present living, breathing, vibrant individuals telling their own stories, *humanising* their condition and bringing stories of hope rather than despair to those who view the films.

More often than not, intellectual and physical disability present with rare genetic diagnoses. The way in which diagnoses are discussed and presented to parents are by their very nature, deficit orientated, signalling the challenges and obstacles that

accompany said diagnoses. Additional resources and stories of people living with rare genetic conditions who experience fullness in their lives are critical in offering families, health practitioners, educators, service organisations and the wider community alternate pathways for supporting people with disability in reaching their full potential.

Rick has travelled to Australia on a number of occasions presenting at various conferences, including the SSBP International Research Symposium, Albinism Fellowship of Australia Conference and the Chromosome 18 Research & Registry Australasia Conference.

Let's hope he visits our shores again in the near future and that we see *On Beauty* on screens soon!



LINKS:

Kartemquin film website: <https://www.kartemquin.com/films/on-beauty>

Facebook: <https://www.facebook.com/OnBeautyFilm>

Twitter: <http://twitter.com/onbeautyfilm>

About Positive Exposure: <http://positiveexposure.org/about-the-program-2/>

IMAGINE ID

IMAGINE ID is a team of researchers, doctors and geneticists studying the links between rare genetic conditions and behaviour in children with intellectual disability. The research group is based in the UK but they are interested in families worldwide.



The story so far....

Over 300 families from all over the world have now taken part in the study. Our initial analysis highlights just how unique children with rare chromosome disorders are. There is a huge amount of variability between the behavioural difficulties of children with different genetic conditions. The behaviour of children with intellectual disability is often described as “challenging”, but this is only one piece of the puzzle. We are learning that, although children may have some symptoms of a number of conditions, these are not always shown in the way that means they receive a specific diagnosis. This means that children with significant needs may not receive enough help. It motivates us to keep doing the research we are doing to find out more about the link between genes and patterns of behaviour.

Get involved

To participate in **IMAGINE ID**, your child must be between 4 and 18 years old. Taking part involves filling out secure online questionnaires about your child's development and behaviour from the comfort of your own home. This will take approximately 3 hours.

After participating, you will receive a personalised summary report which you may find useful when your child is undergoing assessment for services, school or specialist treatment. Here are some comments from those who have received reports:

“I am very happy with the summary report. It will be very useful when my son is changing from one school to another as it summarises all his difficulties.”

Nieves from Sleaford

“It was great to receive the report. I have shown it to the Educational Psychologist and we are using it to apply for extra help.”

Nicola from Coventry



If you are interested and want to find out more about the **IMAGINE ID** study, please read our Invitation Booklet at: www.imagine-id.org/sites/default/files/Invitation.pdf or contact us by telephone on +44 (0)1223 254 633. Alternatively, you can email us at: imagineld@cimr.cam.ac.uk. We are very happy to answer any questions you have. If you do get in touch, this does not mean you have to take part.

IMAGINE id

A study of intellectual disability, mental health and genetics

IMAGINE ID is a research study that seeks to increase our understanding of children and young people with intellectual disability. The IMAGINE ID team is very keen to learn more about the link between behaviour and wellbeing in children with rare chromosome conditions.

The research group is based in the UK but they are interested in families worldwide. Taking part involves filling out secure online questionnaires about your child's development and behaviour from the comfort of your own home. This will take approximately 3 hours.



After participating you will receive a personalised summary report which you may find useful if your child has assessments for services, school or specialist treatment. Here is a comment from Nieves from Sleaford on her child's report:

"I am very happy with the summary report. It will be very useful when my son is changing from one school to another as it summarises all his difficulties."

Get in touch if your child:

- is 4 to 18 years old
- has a genetic change
- has intellectual disability, learning difficulties or developmental delay

Find out more:

+44(0)1223254633

imagineld@cimr.cam.ac.uk

***Our Voice - Loud and Clear* begins in Queensland**

Veronica Wain



A new chapter has begun in Queensland with the formation of the first branch of Our Voice in recent months. With the support of Parent to Parent and Spiral, a group of sixteen passionate people have been brought together to begin their journey as self-advocates with a shared vision of sharing their knowledge and learning with their wider community.

Spiral's Kathy Walker was approached earlier this year about her interest in becoming a facilitator to lead an Our Voice branch. Kathy has worked as a lifestyle facilitator for over seven years and has a passion for her work in the sector. She brings many talents to the role, not the least of which is an understanding of the need for people with intellectual disability to be supported in becoming self-advocates. Kathy has led three sessions with the group with the first being an introductory session being an opportunity for people to come together, with their carers and parents to learn about the aims of Our Voice.



The following session was devoted to brainstorming a name for the group. This was quite controversial with a number of creative names being put forward. A formal vote was taken and Loud and Clear was the final choice. A keen supporter of the group, photographer and support person, Gina Gale then set about creating a logo for the group and providing some foundations for developing some marketing collateral

that will be used to promote the group in the hope of attracting sponsorship. Business cards are also being developed for the members so that they have a tool with which to open conversations about their roles as self-advocates.

The third session included some preliminary discussions about choosing a state representative and five candidates were nominated. This session also involved a handshake workshop, highlighting the benefits of a professional handshake, eye contact and body language.

The five nominees presented their cases to the Inclusion Australia's agency member, Jodie Wolthers, General Manager of Parent to Parent and Heather Carney, Manager of Spiral, another disability service organisation based in Nambour. Miss Kate-lyn MacKenzie was chosen to be Queensland's first Our Voice representative and is delighted to take up the role.

Kate-lyn and fellow member Allycia Staples were supported by Kathy to attend a Queensland Advocacy Inc Seminar in Brisbane where they were exposed to a "bigger picture" of what their roles will involve. They were able to spend time with Mary Mallet and Bob Lees and gained much from their day.

The new group have a number of goals they would like to achieve in their first year including the creation of a website and Facebook page and approaching businesses for sponsorship to cover costs associated with their ongoing meetings and education.

They have been most appreciative of the assistance of Valid for the posters about Advocacy that have been shared and used in their initial meetings.

Loud and Clear are looking forward to building their skill base and welcome any assistance and advice from all involved in the sector.

The founding sixteen members are:

Kate-lyn Mackenzie (State Representative)
 Marke Bowden
 Megan McLeod
 Ken Cleaver
 James Humphries
 Dean McMahon
 Tim Orton
 Allycia Staples
 Kate Paterson
 Graham Eastwood
 Colin Cowlin
 Norman Kirk
 Kate Gadenne
 Jason Rosendahl
 John Davis
 Will Harrington

The group will be supported by Kathy as their lead facilitator with Blaze Ireland assisting and Gina Gale supporting the group with photography, video and graphic design. For the video link, go to:
 Loud and Clear Queensland/Advocacy Group - YouTube.



The Gift of One

Camilla Downs

One blood test, one phone call, one moment in time drastically changed the direction of my life forever. I know more about genetics, chromosomes, DNA, motor skills, verbal skills, and now emotional and behavioural issues than I ever thought I would need or want to know.

My first born child, Lillian, was born one month early on September 14, 2001. She was perfect and weighed 4 lbs 5 ounces. The doctor thought that she was no longer getting nourishment from the placenta and for that reason she was brought into the world a month ahead of time. Knowing what we discovered a few years later, that would explain why she was so small and didn't seem to be growing.

Due to Lillian's delays in so many areas at age 3, Lillian's paediatrician recommended, and we obtained, a Karyotype blood test to rule out any genetic issues. During dinner one night in December 2004, we received a call from Lillian's paediatrician. She apologised for calling so late but had received Lillian's test results that day and felt she needed to call. The Karyotype results showed that Lillian is missing the short arm of chromosome #18 due to an unbalanced translocation. The long arm of chromosome #14 took the place of the short arm of one of the copies of #18. This rare condition which affects only about 1 in 50,000 does not have a "name" and is simply called 18p- or 18p deletion.

I thought I had life pretty much planned at that point and, for a while, this brief phone call seemed to have caused my life to break apart like a melting iceberg with pieces scattering here and there. Looking back now, all that was brought into my life, all that occurred, all that began, and all that ended were meant to happen for my own growth and enlightenment – an enlightenment I feel spreads far beyond myself and my family as I believe we are all connected.

The main way that 18p- manifested for Lillian earlier in life was that she had delays with motor skills, articulation issues, anxiety, fears and gastrointestinal concerns. Now at 13 years old, Lillian is very hard to understand when she speaks. She simply cannot articulate in the way most of us can. The shape of her mouth and the inability for the tongue, lips and mouth to coordinate properly are what cause this. She is a smart young lady and has all the words and thoughts she wants to say in her mind, but simply can't get most of them out in an understandable way.

Lillian's brother, Thomas, was born in November 2005. He was healthy and double the weight of Lillian! Just over a year after Thomas was born, in December 2006, I separated from Thomas and Lillian's dad and, in September 2007, we were divorced. I know some are of the opinion that having a child with disabilities is too much strain for many marriages to handle. In our case, I feel that this would be at the

bottom of the list for why our marriage failed. It was simply a union that was not meant to last. So began this journey of being a single parent to Lillian and Thomas.

Although Thomas has not been diagnosed with a disorder, had I pursued a diagnosis for him as a toddler, and even now, I feel sure that he would be diagnosed with Sensory Processing Disorder, and ADHD, or something similar. I feel certain as I've spent enough time in this world of differences to recognise the signs. I have chosen not to have him diagnosed and for now I use techniques that I have used with Lillian and other techniques and skills that I have taught myself. The underlying theme of all techniques that I parent with and model to Thomas and Lillian is one of mindfulness, spirituality and loving kindness.

Thomas is a true gift and teacher extraordinaire. Just when I think the things I teach and model go unseen and unheard, he says or does the exact thing that was needed. He says things like, "One gift is always free ... LOVE" and "This is the BEST day of my life." He has an innate empathy for those younger than him, the underdog and those who are different. Last April, Thomas completed a photo-a-day project. Every day for 365 days, he took a photo of a LEGO photographer taking a photo and posted it on Instagram. As soon as his publisher (me) has the time and money, this will be made into a book.



We call ourselves Team TLC to correspond with the first letter of each of our names. I believe it was in 2009 that I felt we were drifting apart and that we needed something to bring us back together. The idea to start referring to our family as a team settled into my heart when another mother commented that she treats her family like a team. While pondering this thought, using the first initials of our names came to me. I was so excited when I discovered what our initials spelled.

Thomas and Lillian loved the idea and so Team TLC was born. We even get mail addressed to Team TLC. It was and is a true blessing.

We got rid of our television in 2008 and have been without one since. I simply did not want the kind of energy that is broadcast via television shows, movies and commercials. We have a long standing tradition (since Lillian was born) of having a movie night once per week. I usually get our movies from the local library. We watch them using a MacBook Pro and a projector. It's something that is very meaningful to all of us. I put much thought into the type of movie we watch – only movies with little to no violence that have an underlying theme to which I am in agreement AND movies that make us laugh. Laughing is so good for us.

Whenever I share that we don't have a television, many times I get asked, "What does your family do?" We take lots of walks, play board games, card games, Bingo, read, read, read, go to parks, draw, write, and sometimes we cook together. It is my sincere hope that by eliminating television and limiting screen time that I am helping there to be three more people in this world who know that happiness and peace are within us and not outside of us.



Going on a monthly date with Thomas and Lillian separately is another special time that I share with them. Thomas and I usually go for a walk somewhere beautiful, sometimes out to eat, sometimes to the pet store or to the toy store to look at LEGO sets; sometimes we visit a huge home furnishings store, pick out the furniture sets we like and pretend, and sometimes we visit the used book store and have fun picking out a book. Lillian and I usually go somewhere for a gluten free dessert, sometimes out to eat, sometimes to one of our favourite parks to read and throw the frisbee, and sometimes we visit the used bookstore too. I try to make sure I have a monthly date day with myself also. If Thomas and Lillian are able to spend the night with grandparents, I stay home and read and sometimes watch movies. If I have to leave the house, I may treat myself to lunch or coffee, go for a walk and sometimes to the library to write.

When Lillian was about 7 years old, she got her first computer. She was advanced with her reading skills and had so much to say, yet could not get the words out. I felt strongly that she needed an outlet to express herself. She hasn't stopped since.... I created a blog for her shortly after that and she actively blogs on her website (LillianDarnell.com). She writes book recommendations, short stories and poems. She is being home-schooled currently and also shares research assignments on her blog.

Lillian enjoys the chance to be artistic in many formats. She created an abstract drawing in 2012 that we titled "The Egyptian Eye". We recently sold prints of it to help pay for attending the 2015 Chromosome 18 Registry & Research Society Conference. In fact, Lillian is pretty amazing when it comes to expressing herself through the arts. As mentioned above, she writes short stories, poems and creates illustrations. Most of her content involves nature and fairies and is always fantastical and imaginative. I find her stories and poems extremely moving.

Here are two poems she wrote in 2011:

“Life is so happy, it makes me cry. And I cannot, tell a lie on April Fools. The point is that you will have a non-stop loveable brain. And it has our choices in it.”

“A poem is a sweet brainer. You listen to music. And the point is that your creative brain is a bank. And listen to it. I love you a lot of pretty flowers.”

In fact, Lillian is soon to be a published author as soon as her publisher (me) has time to pull together the poems she’s created over the past 6 or 7 years. Lillian loves to create her own made-up games and can literally get lost for lengthy periods of time playing with shadows. She delights in making everyone in the room aware of the shadow adventures.

She is also an amateur nature photographer and continues to perfect this by the day. When she was around 4 years old, she loved taking pictures of food. I have been an amateur nature photographer for the past several years and she seems to enjoy this as much as I do. There’s just something about being amongst the beauty of nature and capturing it in one’s own unique way. Another of Lillian’s passions is tracking the weather. She follows local and non-local storms, humidity levels and many other weather occurrences. She has a nightly ritual of sharing the humidity percentage with me and watching nightly Accuweather videos.

A hobby of mine is to be aware of and notice heart shapes in rocks, clouds, leaves, flowers, nature, food, and even bird poop. I take pictures of almost all the hearts I come across and share the pictures on social media. Thomas and Lillian have become my helpers with this hobby and thoroughly enjoy discovering heart shapes almost every day. With excitement they will find me, lead me to their heart discovery, and say, “Aren’t you going to take a picture?”



Lillian has always had anxiety and worries related to certain situations, venues, and schedules. Some of these are stairs, escalators, people with stern voices, automatic flush toilets and hand dryers, small enclosed areas and big open areas. In addition to a fear of all animals and stuffed animals. Some of this stems from difficulties with Lillian’s proprioceptive system and some from sensory processing issues.

I am still on this journey of attempting to learn Lillian’s nature. I’ve come a long way. What I do know, what my internal compass is rock solid about, is that Lillian’s contributions to humanity will not come forth in the typical way of going to school, graduating, going to college, and getting a job (or some adapted version of this). And something else I know is that it’s okay if there’s a shift within her and she does go the typical route. She is an artist and her contributions are manifesting and will continue to manifest in this way. As I write this, I realise, she’s got something figured out that many of us strive to figure out our whole lives. How to be yourself and how to express yourself. And how to express oneself in a way that benefits humanity and spreads loving-kindness.

Lillian loves and enjoys life. In fact, she is confused when, at her prompting, I or those around her don't stop what they are doing and BE in the present moment, enjoying life and being happy.

In December 2014, Lillian caught a pretty bad cold. At the same time we had just attended her transition IEP for moving to middle school next year. Internally, Lillian's teenage hormones were making their appearance as she had just turned 13 in September. Illnesses take a harder toll on Lillian, even if it is just a cold. She missed some days of school, went back for one day and then seemed to get sick all over again. Her cold had turned into a sinus infection.

After the sinus infection cleared, Lillian refused to go back to school. This wasn't just a case of Lillian being stubborn and defiant. I could sense a deep fear and high level of anxiety. I tried to help Lillian through this time by addressing and solving whatever it was that was causing the fear and anxiety. During this same time, Lillian's ability to cope and remain calm seemed to be dissolving. Whenever her schedule was changed or didn't work out or things didn't go as she thought they should, she would go straight into a horrific meltdown with an explosion of screaming, hitting, pinching, and scratching. It was lightening fast with hardly any space between something going wrong (in her mind) and the explosion.

At this point, I decided that I needed professional help. In April 2015, I finally located an acceptable psychotherapist that took Lillian's insurance to work with Lillian and I on mindfulness techniques, dialectical behaviour therapy, and cognitive behavioural therapy. I know that there are medications to help with these difficulties but my inner compass is very strong in that I am supposed to try the non-medicated route first. I absolutely do NOT judge other parents for the routes they take on this complicated and complex journey. The part of me that would have judged no longer exists within me, thanks to Lillian and Thomas.

It was (and is) my intention to help Lillian be in tune with her body's feelings and emotions so that she can recognise when anger or sadness are present. And to then have her use mindfulness techniques and emotional connection to connect with negative (and positive) emotions. First and foremost to get her past the point where she feels out of control leading to screaming and lashing out at others (myself and her brother, Thomas).

This is furthering my own mindfulness learning as I must be mindful when Lillian disconnects. I must also be patient, flexible, and learn how to not take words or actions personally. There are absolutely days and moments my thoughts go straight to, "It's time to look into medication." However, once the moment has passed so has the thought. As long as we are making progress we'll continue this path. Although Lillian has not returned to school yet, we are making slow progress. I use the term we as this is definitely a team effort by all three of us.

She had one extremely huge meltdown turned into explosion this past July. We made a quick stop at the grocery store to get a few items. I was a bit overwhelmed as the store was super crowded. I was trying not to forget what we needed and to carry on

small talk with Lillian. We took a few minutes to smell the essential oil perfumes and wonderful handmade soaps. Then we chose a gluten free cookie for all three of us. After this, I decided to return an item since we were close to the customer service counter. The wonderfully kind cashier offered to ring my other items since I only had a few. I accepted. Lillian had caught up with me at this point and once I was finished paying, I could sense her energy shift.

Apparently, there was miscommunication between the two of us about Lillian looking at more gluten free desserts. This quickly led to a volcanic like explosion for Lillian with screaming and lashing out at me. Fortunately, I was close to the exit doors, so I made my way out and headed to the car with Lillian screaming and yelling behind me. I quickly got into the car and invited Lillian to do the same if she was going with me. She was not open to doing any of the mindfulness or other techniques we've been learning.

I decided to start making our way home even though she had not calmed down. Perhaps not the best choice in that moment. She was scratching, pinching, and pulling my hair from behind. As soon as it was possible, I pulled over, turned to Lillian and screamed some ridiculously outrageous comments, and decided I must get out of the car. We needed space between us as I was in a great deal of pain from the scratches and she was a big hot mess. Once out of the car, I closed my eyes and asked to see the situation differently. I opened my eyes and shining up at me from the rock and dirt filled ground was a beautiful red jewel heart. I knew that was in answer to asking to see it differently and a reminder to always respond with love. (I have a picture of this if you want to include it.)

At this point, Lillian was ready to do a calming technique and I requested that she do it on her own. She got out of the car and chose to pick up a couple of rocks and study them. After a few minutes we got back into the car and drove home. We've not had anything of that magnitude happen since then and I am hopeful this was simply "one step backward" before more steps forward. When this happens for Lillian, one of us has to be fully present and mindful or things can escalate.

Thomas does not escape having a meltdown here and there also. As I shared earlier, he has sensory issues and his thinking is extremely linear right now. We were at a small theatre last night which was packed. A presenter was being announced with much fanfare and loudness. Thomas almost could not stand it. He was shivering and had his hands covering his ears. At the annual Chromosome 18 Conference this past July, during the farewell dinner, the microphone made an ear piercing loud squeal. Thomas got so scared that he turned pale and had to come sit next to me.

At the conference there is always a sibling track. Thomas has been a part of the sibling panel for the past two years so I signed him up again this year. He mistakenly thought I signed him up to only be involved in sibling activities and to not be in the "day care" room with the young self-advocates (those his age and younger). He had quite the meltdown about this, declaring that he wanted to be with the kids like

Lillian because they get him. He certainly has a special connection with his self-advocate friends.

I began to expand my awareness right about the time I got married in October 1998. I could not sleep one night, got up, and turned on the television. Stephen Covey was being interviewed about his book, "The 7 Habits of Highly Effective People". It was the exact message I needed to hear and that began a 17 year journey (and still counting) of seeking and devouring similar books and materials. This journey began with self-help, self-improvement, parenting, and entrepreneurial books and has since transitioned to personal growth, self-healing, mindfulness, and spirituality.

It is my belief that humanity is blessed by and with children with intellectual and developmental disabilities to help us shift towards love and acceptance of all of humanity. In addition to breaking us free of the "it has to be done this way" mentality. For those like me this certainly does involve learning empathy and compassion with mindfulness as a base and breaking the old inflexible habits of relying on what we thought was right and wrong and acceptable.

Having Lillian and Thomas in my life has brightened and expanded my life in an amazing way. I have released long held judgments, learned what it really means to be patient and flexible and how to look into the eyes of another and know that we are one and that person's actions and words are not coming from their true self.

This has also been about learning that what causes me frustration with each of them, has to do with me and not them. The pre-Lillian me was severely judgmental of single moms, other people's parenting skills, and those in financial hardships. This has completely shifted for me. I am human, and still do have judgmental thoughts arise. However, most times I notice them and do not voice these harsh thoughts against my fellow brothers and sisters.

At times, I know that it may look to others that I've got this all under control and I make it look easy. Believe me, it's not always as it seems. I parent Thomas and Lillian alone. With both of their issues and Lillian's therapy appointments and mystery ailments, a traditional job simply does not fit that equation. I have yet to recover financially from the separation and divorce. All bills and debts were solely in my name.

In 2008 when I could no longer pay for our car, I chose to make it a celebration of welcoming the new instead of an occasion to mourn. I did this to make it easier for Thomas and Lillian and I feel every ending is a new beginning. On the day we were to return our car we baked cookies, wore party hats, and listened to happy music as we cleaned out the car. One winter we had record breaking cold temperatures. Our furnace quit working, was not repairable, and I did not have the money to buy a new one. I moved us all into the master bedroom with three oil heaters and closed the doors. We pretended we were basking in the warmth of a tropical island.

Bitterness, anger, and victim mentality are no longer deeply present within me. This doesn't mean that I no longer feel these and other negative emotions. They are a part of humanity and will continue to be experienced. However, I have learned skills and

techniques to connect with emotions, to be with them, and learn from them. Once we learn what an emotion is attempting to teach us, it dissipates on its own. This is just simply something that happened, and I feel this happened in furtherance of my own growth and learning how to be me, to share my true gifts and talents, and to earn money for my family by expressing myself and those gifts.

I am an author of a best-selling book, life coach, and substitute teacher at Thomas and Lillian's school - High Desert Montessori School in Reno, Nevada (although, Lillian is being home-schooled right now.) With each of these expressive "jobs" I get to be me and bring my life's experiences and gifts to share. In addition to these, I have a daily meditation practice, am a student and teacher of mindfulness and emotional connection, love taking walks, and love photographing nature.

Since the night of receiving the gift of not being able to sleep and hearing Stephen Covey share his message, I have been on a journey of awakening to my own worthiness, the treasures and gifts that I have to share with others, peace, and a love of all humanity, animals, and nature. This has been an incredible journey of receiving gift after gift; with some of these gifts wrapped around some painful moments and events.

A major concept that I have learned over these past 17 years is that one should try to remember to always respond with love in all circumstances. When we remember this, miracles happen. I define a miracle as a shift in perception as well as synchronistic occurrences.

The three of us, Team TLC, are a perfect fit to be a part of one another's journey in this life. I feel it is no accident that we are a family and I feel we are each mirroring the facets of one another that we would like to shift. There are certain moments I feel anything but blessed and grateful for this journey. However, in moments of being true and mindful, I am indeed extremely blessed and grateful for the gift of enlightenment birthed by Team Members Thomas and Lillian.



Camilla Downs is a Mom, best-selling author, life coach, speaker, facilitator, and amateur nature photographer. In the spring and summer of 2015, Camilla prepared for and facilitated a Parent to Parent *Support Parent* training hosted by Family Ties of Nevada. Camilla's book "D iz for Different - One Woman's Journey to Acceptance" was a #1 Best-Seller in Special Needs Parenting and #2 Best-Seller in Self-help. She lives with her two children, 13 year old Lillian, and 9 year old Thomas in Reno, Nevada. Lillian has a genetic abnormality called 18p-.

Camilla has studied self-help, spirituality, mindfulness, self-actualisation and emotional connection for the past 17 years. She feels her life purpose is to share openly with others her own experiences, growth and learning, which she does through coaching, social media and her blog. Camilla's coaching sessions are unique in that they can be as short as 20 minutes or as long as 60 minutes. There's no homework or goal setting, with the focus being on connecting with and clearing the thoughts, feelings and emotions that have you feeling stuck. You can learn more about Camilla and her book at www.CamillaDowns.com.

MY WORD !

a reflection on people with disability in society

Christine Regan

THE BALANCING ACT OF CHANGE

This is a selfish column — and later, I want to tell you why.

For some time, I have been growing hoarse talking about change. The whole person-centred thing has been coming towards us from the horizon for ages. Now the NDIS is on its way, and for many it is nearly here.

Big changes are coming and I have been talking to all sorts of people: people with disability, family members and supporters, providers, government and policy people. Some are excited by the prospect of change, some cautiously thinking about it, some interested but wary, some hopeful but cynical, some exhausted and defeated, others ferociously resistant to the idea. There are people who are merely resigned, as if this is yet another trial to be endured on an unwelcome journey.

It worries me that such a positive opportunity of possibility for people with disability as the NDIS can be viewed by anyone at first with derision, before it has even had a chance to succeed. Why is this so? I have given this some thought.

As they grew up, my sons started to do things without their parents. They went to birthday parties, to play at friends' houses, sleepovers, etc. Then as teenagers and young adults, they started to go out, to push the boundaries, to go on separate holidays, to carve out an independent life. They began to "break away" from the parental home in a natural process over time.

For my daughter with disability Erin, it was a different story. Sure, she stayed at Grandma's place and we had her friends over, she went on camps and assisted holidays. But WE had to facilitate these activities and occasions. These times away all involved us as her parents to some extent. They were not self-initiated in any real sense.

As young adults, my sons made their own decisions at the big moments in life or life transitions. My relationship with my sons remained close and loving but they became independent.

Yet for Erin, it was not the same. Decisions at her life transitions involved Erin but included her parents and often others as well. My relationship with my daughter just got closer and closer, increasingly entwined, despite our best intentions and efforts to promote her independence.

For years, the *system* entrenched this entwined relationship. The strong and persistent message from the *system* was "this person is your responsibility as a parent for the rest

of your life and all the consequences are yours." If there are significant medical or other needs, as occurred at times for Erin, the relationship can further deepen.

Additionally, it takes a measure of patience, networking, negotiation, balance and sometimes compromise to arrange support services by, with and for a person with disability, to get a good provider on board, for the person with disability to accept the supports and to organise the rest of your life around those services. It can be a delicate balancing act to manage the medical needs, support needs, social and physical needs and still promote the personhood and independence of the person with disability.

This is why the prospect of change elicits strong emotions in some family members and also in some people with disability who manage their own lives.

It is also why the change is so necessary.

For too long, too many people with disability have not been the drivers of their own lives. For too long, too many people with disability have not been encouraged or supported to be the drivers of their own lives. The NDIS will put the person with disability at the centre, Erin in the driver's seat where she should be, with her family and friends to support her.

But the change to the NDIS must be managed with sensitivity and understanding, balancing the excitement of positive possibility against allaying the fears that could derail the process and progress for everybody.

The success of the change to the NDIS will put people with disability in the driver's seat with the close and loving support of their family where they want and require it – as it should be.

So why is this my selfish column?

I suppose because personally I find the prospect of change a little frightening and very exciting and the process of change a bit daunting. Also, because I selfishly want the best for Erin and I believe the NDIS is the way to get there.

And the best for Erin should be of **Erin's** choosing, *not* her mother's.....

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Christine has worked in various non-government and government roles in the disability and community sectors in New South Wales since 1987. She has held memberships on the Boards of National and NSW Councils for Intellectual Disability as well as the NSW Anti-Discrimination Board and the NSW Ministerial Reference Group on Person-Centred Approaches. She is one of the founders of a local disability advocacy organisation and was chair of their activist group.

Christine is the proud parent of three adult children. Her daughter Erin has Down Syndrome and lives at home with Christine and her partner.



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