

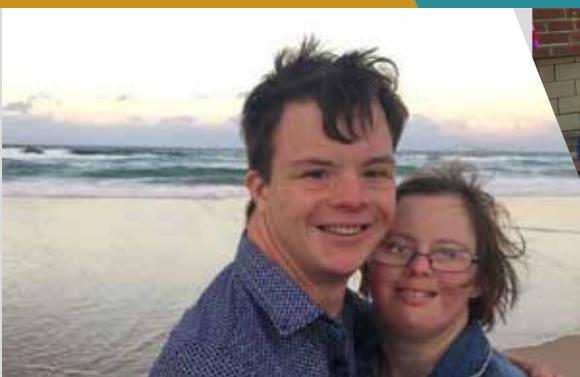
your voice your choice

OCTOBER 2016



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Welcome to Your Voice, Your Choice

Hi, and welcome to the Your Voice, Your Choice monthly newsletter from The Disability Trust.

This month you may have noticed that we have a new format. What do you think? Let us know at info@disabilitytrust.org.au.

This month we catch up with Quentin Kenihan, now 40 and with a new book "Not All Superheroes Wear Capes", we hear from a father of a child with a disability on how his role has changed, we look at the

case of Andrew and how Centrelink have made him prove he deserves a pension even though he has been in a group home for 17 years, we look at the love story featured on Australian Story, we look at the Deaf Body in Public space and as usual we have the NDIS update with all the latest details on the NDIS.

"Your Voice, Your Choice" aims to provide the questions, and hopefully most of the answers, that will keep you informed and able

to use your voice to achieve your choice.

If there is a topic, issue, program, funding, article, event, or anything for people with disabilities, their families and carers, and people working in the sector, that we should know about, then contact us at info@disabilitytrust.org.au.

Editor: Sean O'Neill

The Disability Trust NDIS Services. Trust in Us.

The Disability Trust is a highly respected provider of services to people with a disability.

You can Trust us to provide the supports you need to live the life you choose!

The Disability Trust covers an area from South East Sydney, to South West Sydney, south through the NSW Southern Highlands, Goulburn, Queanbeyan and the ACT, Cooma and south east to Bega, and all along the Coast from Sydney to the Victorian border.

Make The Disability Trust your local NDIS provider.

Contact one of our NDIS Support Planners on 1300 347 224 or through our website www.disabilitytrust.org.au, or email info@disabilitytrust.org.au



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Kiama and Shoalhaven

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- Programs, aids and equipment
- Forums and workshops
- Individual advocacy and support
- Referral to appropriate services
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...creating an inclusive world

The newsletter is aimed at covering a wide variety of stories and issues across the disability sector. The views expressed in this newsletter are not necessarily those of The Disability Trust. Should you have a story or information that you would like included in the newsletter please contact the Editor, Sean O'Neill at sean@disabilitytrust.org.au.

Fractured memories: Quentin's remarkable story

Not All Superheroes Wear Capes – Quentin Kenihan's story of growing up with a rare bone disorder and being thrust into the public eye – is not "inspirational porn".

That's Quentin Kenihan's phrase, and one perhaps that could be said to have been the role he unwittingly played from the age of seven when he became a poster boy for disability. Who could resist his against-the-odds pluckiness and his cute little feller never-say-die irascible wit that stared down his condition – Osteogenesis imperfecta – that means his bones easily and constantly break?

But since then, Kenihan, now 41, has ridden a bumpy ride of institutionalism, hospitalisation, parental estrangement and drug addiction.

He has come out the other end, and in the last few years has staged a one-man show at the Adelaide Fringe Festival, acted in George Miller's *Mad Max Fury Road* and now has his own radio interview program.

So what's not inspirational porn about that?

Kenihan, who describes himself as a disability activist, says the last thing he wanted his disarmingly honest book *Not All Superheroes Wear Capes* (Hachette Australia) to be was "inspirational" in the cloyingly self-conscious way some stories about overcoming biological and medical difficulties can be.

"Back in 2005 I sent a draft to a publisher and it came back with 27 pages of notes that said this is too full of angst and doesn't have enough celebrity stories," Kenihan says.

He shelved the book but after the success of his stage show *Quentin: I'm 40. Now What?* He took the advice of comedian

and writer Tim Ferguson (who worked on the stage show with him) to revisit his story with another publisher.

"I told this publisher that I didn't want it to be full of celebrity stories and some sort of inspirational porn. I wanted people to understand the bulls—t in my life as well as the good bits – that's what makes up a life."

And the result is a disarmingly honest and surprisingly affecting book that in many ways is as much about fame itself as about fame because of a disability.

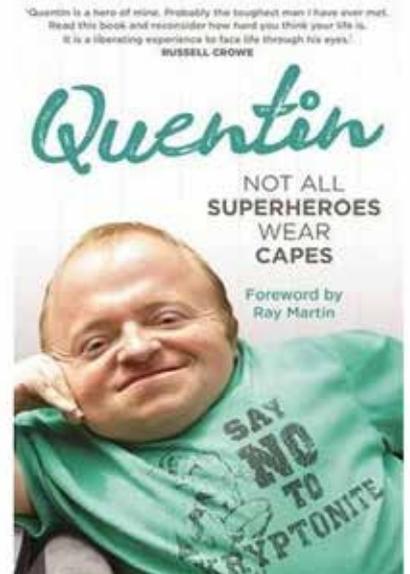
Its opening chapters describe his early childhood memories of parents, siblings, attending a regular school and the attendant difficulties for all of them in dealing with his condition.

However, from age seven after a "Make a Wish" exposure led to a Mike Willesee documentary that made him famous – or a "commodity", as he describes it – there was increasing pressure on his parents' relationship with each other and with him.

The book is heartbreaking and brutally honest when he describes his first night in fulltime institutional care and when visits from his parents become fewer and fewer.

Usually if your child suffered a broken arm, you'd rush to the hospital to be with him, to comfort him, to take care of him and then to take him home to recover.

That's not what happened with me. My mother and father decided that I'd be okay by myself. After all, it wasn't like I



hadn't broken an arm before. If anything went wrong, they figured the doctors and nurses would be there to look after me.

I was stunned. It was the first time that I had been to hospital in years and my parents didn't bother to show up. How could I think anything other than that they didn't care about me anymore.

Where's a pair of ruby slippers when you need them? That was it. I hated them. I hated them with a passion after that. Everything I had ever thought about them had been a lie; all the good they'd done in my earlier years had been thrown out the window. They didn't come the next day or the day after.

For the rest of the article, including what Quentin wrote about Mike Willesee, go to <http://indaily.com.au/arts-and-culture/books-and-poetry/2016/09/26/fractured-memories-quentins-remarkable-story>.

When You Are the Father of a Child With a Disability, Stereotypes of Manliness Disappear

Mel Beck, on how fathering a child with a disability changes everything. Including your ideas about what it means to be a man.

Behold! Fatherhood. Manliness optimized. This is your golden moment as the dominating species and you have everything—a wonderful wife, a great job, a beautiful home, and now, children. You are right on track for a cup runneth over with fulfillment.

Soon to come are baby's first steps, the first day of kindergarten, sporting achievements, first dates, graduations, college, weddings, grandchildren, and more. You are The Man and you are providing for your family. Life could not get better.

Then, KABOOM!

Like the 1960's Batman cartoon, a blow to the head has you reeling and you don't know what hit you. You've just returned from an appointment with a developmental specialist and your baby girl has been diagnosed as severely intellectually disabled. Wait! What? This isn't right. This isn't how it's supposed to be. Your baby girl is handicapped? Disabled? What? You're dazed and confused. This isn't manly.

What should you do? This isn't what fatherhood is all about.

Or is it?

News to you. This is what your fatherhood is all about. You have just boarded a roller coaster that makes few stops. Fathers of disability—take note. A difficult life awaits you, and your family needs you. This is Fathering Disability. Do not let them down.

I'll tell you first-hand, when you come face to face with the incomprehensible world of permanent disability, the future wrecks of hopelessness. The initial heartbreak and disappointment are overwhelming. Dizzying uncertainty is seemingly insurmountable, and you may feel as though you just can't do this. Fortunately, for you and your family, the truth is that you can do this, and you will do this. You must do this.

Does this sound like a high school pep rally? I hope not, because I'm talking serious stuff here. You, your family, and your child are about to scale a mountain of adversity. Gut-wrenching decisions and endless disappointment lurk. You will need to forget everything



you thought you knew about fatherhood.

You must quickly get on board with Fathering Disability and its effect on you and your family. This is parenting and the fundamentals of care-providing at its core. This is truly supporting and providing for your family in some non-traditional ways. It's family first all the way. You and your self-ness are no more.

To that end, you will need to embrace the three R's of Fathering Disability - Redefine Your Manliness, Reset Your Goals and Renew Your Commitment.

For more of this article by Mel Beck go to www.goodmenproject.com/featured-content/the-masculinity-offathering-disability-lbkr.

In care for 17 years, Centrelink still told Andrew to prove he deserved pension

A man with severe disabilities who has been in state care since 1999, was ordered by Centrelink to prove his eligibility for a disability pension.

Andrew Johnson was diagnosed with profound autism when he was four and went into a Department of Human Services-managed group home when he was 13.

The 30-year-old cannot speak, has autism, Tourette syndrome, bipolar disorder, attention deficit hyperactivity disorder, obsessive compulsive disorder, epilepsy, and needs a stomach tube to help him feed.

His mother, Deb Johnson, said she felt "physically sick" after receiving a letter from Centrelink on September 15 demanding evidence that her son was entitled to the pension.

She was given just two weeks to collate the paperwork, which included decades-old documents.

Mrs Johnson was finally granted an extension, but was then told to start preparing for a review for her elder son, William, 32, who has been in state care since 1999, and suffers from profound autism.

But on Thursday, the mother-of-four suddenly received a call from Centrelink saying no further action would be required, citing a letter from Andrew's gastroenterologist as the reason behind the decision.

While Mrs Johnson was happy with the eventual outcome, she was less than pleased with the process.



"They have put me through absolute hell," she said. "I have been really severely stressed. I have been to four appointments in a week, three specialists and one GP."

"I can't believe they have accepted just a gastroenterologist's report and say it covers all disabilities, when they have asked us to jump through hoops with [documents showing] onset of symptoms, dates of diagnosis, and an IQ test," she said.

"They haven't got one report from me that I have collected in the [past] week-and-a-half."

A Human Services Department spokeswoman said William would not be subjected to a review because the department had the information they needed for him to continue to receive his payment. There was no comment offered on why Andrew was called in for review in the first place.

Accessible Parking Protest



In Lisbon, Portugal, wheelchair users found a unique and poignant way to protest improper use for disabled parking spaces. Weekenders out for a day in the park were surprised with no

available parking; instead, every space was filled with a single wheelchair.

Each chair was accompanied with a message, like "I'm just getting coffee" and "It'll only take a minute," and all the other verbiage used as justification for improperly parking in a parking space designated for the handicapped. Some chairs even came with owners, who were ready and willing to offer up one of these excuses!

Similar initiatives have been carried out in Vila Real, also in Portugal, as well as Boa Vista, Brazil, on their National Day

of Struggle for the Disabled.

In NSW you can report cars illegally parked in Accessible parking spots on 1300 884 899.



Down syndrome testing results delivery to change nationally following Tasmanian complaint

The results of prenatal testing for Down syndrome will be delivered differently, to ensure women are not swayed to terminate their pregnancies.

Changes follow a complaint to Tasmania's Anti-Discrimination Commissioner around the use of negative language such as "risk" during a diagnosis.

The complaint was lodged by Launceston woman Rebecca Kelly, whose four-year-old son Ryan has Down syndrome.

"[Women] are often given the diagnosis in negative terms, so first of all talking about 'a risk' — 'I'm sorry, I have some bad news, the results are back and there's a high risk,'" Ms Kelly said.

"We don't talk about the risk of winning Lotto, we talk about the risk of people dying of cancer. Risk is inherently associated with bad outcomes."

Tasmania's Anti-Discrimination Commissioner found the use of

negative language in a Down syndrome diagnosis could breach the Anti-Discrimination Act.

It has prompted a change in the national guidelines for prenatal testing.

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists guidelines now point to more neutral terminology like "chance" or "probability".

Ms Kelly hoped the move would reduce the stigma around a Down syndrome diagnosis.

Deaf Jurors Serve in USA and New Zealand, but not in Australia

There is widespread anger among deaf people after the High Court rejected an appeal over their eligibility to serve on Queensland juries.

Deaf jurors serve in the United States and New Zealand and several independent reports recommended legislative change to allow deaf jurors in Australia.

The case was brought by Ipswich woman Gaye Lyons, who argued she was discriminated against when excluded from consideration for a Queensland jury in 2012.

"Angry, yep, frustrated," she said through an interpreter. After five years of struggle, just fighting for access for the Australian deaf community, it felt like a slap in the face."

The High Court found she was not qualified to serve as a juror because

the Queensland Jury Act does not permit an Auslan interpreter to be present during jury deliberations.

Ms Lyons described the High Court decision as discriminatory.

"If the courts are willing to use interpreters in courts for any other cases, like murder cases, they use them in the Family Court and they trust interpreters to work in those settings, what's the difference with trusting them to relay in a jury room?" Ms Lyons said.

"What's the difference if they work in court anyway?"

Western Australian law already allows deaf jurors, although it is believed no deaf person has served on a jury there yet.

Ms Lyons and deaf advocates are calling for legislative change in

Queensland and other states to allow deaf jurors.

It was also

recommended by several reports, including one from Queensland's own Law Reform Commission in 2011.

Ms Lyons, who previously worked for advocacy group Deaf Australia, plans to keep fighting.

"I'm not going to be giving up. I'm not doing it for me, I'm doing it for my community.



Couple's love story captures hearts

A young Queensland couple with Down syndrome say they are overwhelmed about the reaction to their



love story, which has resonated with people around the world.

The story ABC's Australian Story about Michael Cox and Taylor Anderton's journey to attend a debutante ball for people with disabilities on the Gold Coast has had more than 12 million views on social media.

The pair met at a swimming carnival six years ago and their relationship became serious last year when Mr Cox proposed while holidaying in the United States.

The Australian Story episode discussed how when Michael Cox and Taylor Anderton became an item their parents were delighted their adult

children, who both have Down syndrome, had found love.

But when the couple, both in their early 20s, started talking about weddings and babies, their parents became alarmed. Now, the families are wrestling with Taylor and Michael wanting "adult things": sleepovers, sex and a honeymoon in Vegas.

Michael and Taylor believe their parents are being overprotective, as do disability advocates. Both sets of parents fear the consequences of a baby on all of their lives.

Mr Cox said the couple had been overwhelmed by the reaction to their story.

"My brother saw it in London — he loved it," Mr Cox said.

"He's shown a bunch of people over there. A few of my mum's mates thought it was our wedding.

"I think my favourite part [of the video]

was when we were dancing together and then next minute I leaned in and gave her a kiss."

Mr Cox's father Simon said he had been approached by international media to tell their story.

"I just can't comprehend it," he said. "We were excited when there was 200 views on it and someone's just said it hit [almost] 12 million today.

"We've been contacted by American TV and a lot of Australian magazines.

"The kids just came across really, really well, but that's just the way they are."

Ms Musk also said she was incredibly proud of her daughter.

"Everyone said: 'We've got tears in our eyes' — that's been the main reaction," she said.

See the Australian Story episode at www.abc.net.au/austory/content/2016/s4539439.htm.

Children locked in dark 'cell like' room at NZ school

Children were repeatedly locked in a darkened, cell-like room at a primary school as punishment for bad behaviour.

New Zealand Education officials launched an investigation at Miramar Central School in Wellington after a behaviour therapist found an 11-year old disabled boy alone and distraught in the cupboard-sized room, with no way to get out.

The boy, who is autistic with the mental age of a toddler, was one of at least 10 children - mainstream and special needs - put in the "time out" room within the past year, largely without parent knowledge or consent.

While the use of the room was not illegal, it was "outmoded", the investigation found.

The school says it will phase out the use of the room, however, the boy's mother said more accountability was needed, and was planning to go to both the Ombudsman and possibly police.

"I'm horrified a school would do that," she said. "My son is petrified of the dark and so this would have been a truly frightening experience for him."

"It's their dirty little secret. There's a total lack of transparency," she said.

The mother found out about the room in July, after her son's behavioural therapist, Shawna Chow, went to collect the child from a playground at the school's Special Needs Unit but couldn't find him.

"I asked if anyone knew where he was and a teacher aide told me he was in 'time out'. I've been at that school five years but I'd never heard of it," she said.

When back inside, Chow could hear the boy calling out "I'll be good, I'll be good", but couldn't see him.

"I was running from room to room saying 'yes you're good, it's ok, it's Shawna'. Eventually I found a door but I couldn't open it."

By the time a teacher aide unlocked the room the boy had been in there at least 10 minutes.

Chow said she felt the school did not understand the child's disability or the consequences of what they'd done, which she said would have a lasting psychological effect.

The boy's mum said he still has night terrors. She has pulled him out of the

school, but he sometimes still says "no dark room" and refuses to have the bedroom or bathroom door shut.

The Ministry of Education investigation found he had been in the room at least 13 times over nine days. At least 10 other children had been in the room since 2015, for up to 25 minutes at a time.

The room measured 1.45m by 2.3m. It had an external lock, a high window, and limited natural light. According to school guidelines, a staff member was supposed to monitor students inside at all times.

An incident log said reasons children were put in the room included hitting, making a mess, disobedience, and a lack of focus. It was also used as a threat when children were misbehaving.

"Some staff saw the time out room as an opportunity for students to self-regulate, while most saw it as a consequence for an undesirable action," the report said.

The investigation said although staff had the best intentions, the room was out of date, and would not meet soon to be released guidelines on seclusion and restraint.

The Deaf Body in Public Space

"It's rude to point," my friend told me from across the elementary-school cafeteria table. I grasped her words as I read them off her lips. She stared at my index finger, which I held raised in mid-air, gesturing toward a mutual classmate. "My mom said so."

I was 6 or 7 years old, but I remember stopping with a jolt. Something inside me froze, too, went suddenly cold.

"I'm signing," I said out loud. "That's not rude."

As the only deaf student in my elementary school, I had already stumbled across the challenges of straddling two languages and two modes of communication. My family was hearing, but they still empowered me by using both English and sign language at home.

A sign language interpreter accompanied me throughout the day at school, and my teachers created a welcoming environment for me to learn, but finding a place to belong with kids my own age often felt more difficult. I tried to speak to them, and occasionally they reciprocated the effort by learning some basic signs. But usually I felt separate.

I went home that day and asked my mother about what my friend had said. "Don't worry," my mother said, "she doesn't know the social rules are different with signing. You aren't being

rude." With that, matter-of-fact as always, she brought the conversation to an end. But I still felt a lingering self-consciousness, entirely novel and difficult to shake.

This was perhaps the first time I realized that other people could see me as obtrusive, as taking up too much space, when I was simply communicating just as I was.

When I reflect on this memory two decades later, I recognize how my childhood friend, whom at the time I had found to be so accusatory, had really gaped at me with a sort of wonder. My signing challenged the rules of social conduct she'd absorbed from adults, and to her I must have seemed ignorant or radically rebellious, or perhaps both. But pointing was a truly fundamental act for me; it was how I expressed what my grown-up scholarly self would call relationality — the idea of being in the world in relation to others. Through sign language, a properly poised finger allowed me to say you and me and he and she and they. If I did not point, how could I make a human connection?

Many years later, when I was in graduate school, another conversation with a friend made an impression on me. We were in a cafe having lunch; she was one of those rare friends who had started learning sign language solely to communicate with me. That

day over lunch we forfeited spoken English, which we typically used to talk with each other, and practiced conversing with our hands and our facial expressions. I felt a touch of exhilaration; she was putting aside her conventional, ingrained hearingness and coming to meet me in my visual world.

But after a few minutes, my usually bold, un-self-conscious friend stopped. She chuckled and shrugged a little, and said, "I feel like everyone here is looking at us."

I glanced around the small cafe, at all the hearing people sitting at their tables. Indeed, some had craned their necks to look at our movements, but this was behaviour I'd long ago ceased to notice. "Yeah," I signed back, bluntly. "That often happens."

My friend smiled. A moment later, we started conversing again, and I think then she understood: This is what it can be like to occupy a signing body.

For the rest of the article go to www.nytimes.com/2016/09/28/opinion/the-deaf-body-in-public-space.html?r=0.

This article is part of a weekly series of essays, art and opinion by and about people living with disabilities by the New York Times, the entire series can be found at www.nytimes.com/column/disability.

Most Complaints to Human Rights Commission on Disability Discrimination

Commission has confirmed in a Senate estimates hearing that disability discrimination received the highest level of complaints across the board to the commission.

Human Rights Commission president Gillian Triggs and disability commissioner Alistair McEwan told the hearing that disability complaints were on the rise and now made up the highest number of all complaints received, particularly around employment, and goods and services.

"The most recent percentages for complaints about discrimination in employment for people with disability is 35 per cent," Triggs said in answer to questioning from Greens Senator Rachel Siewert.

"With goods and services it is at 33 [per cent]. So you can see we get to 68 per cent which pretty much reflects the kind of balance of the work of the

commission.

"[The number] isn't decreasing at all."

The human rights commissioners were also asked about complaints about the National Disability Insurance Scheme.

"We have received a small number of complaints [about the NDIS] but it is too early to comment about the nature of those complaints," McEwan told the hearing.

Siewert said after the hearing: "Almost two-thirds of complaints received to the commission are either related to employment or goods and services.

"This percentage is reflected in the disability space, but the numbers are much higher than other cohorts, with no signs of decreasing. This must be urgently addressed.

"Discrimination is a serious barrier



to employment that restricts opportunities available to people with disability. This makes it more difficult for people to pursue opportunities and makes secure employment much harder to retain."

She said the government was intent on dropping people off the Disability Support Pension when they must know full well the discrimination that people with disability faced in obtaining employment.

The Biggest Recess

The first Biggest Recess will be held on 28 October 2016 across NSW as part of Children's Week.

This is a great opportunity to focus attention on childhood health through awareness and education in a positive and fun environment.

For more information go to www.biggestrecess.nsw.gov.au.

CARER GATEWAY – A GREAT PLACE TO START FOR SUPPORT

Carer Gateway is a national online and phone service that provides information about services and support available for people who care for someone with disability, chronic illness, dementia, mental illness or who are frail aged.

NSW Central Coast resident Greg began caring for his mum, Lyn, in 1999 and has been her dedicated carer for the past six years. Lyn lives with spinal stenosis and is in a wheelchair with limited mobility.

Initially, Greg says he did not realise that the support and assistance he was giving his mum made him a carer. He did not identify with the term carer.

'I was providing support such as taking mum to her GP and specialist appointments along with social outings and activities, plus cooking, cleaning and other household duties. I began to become more aware that the support I was providing was in line with that of a carer.'

Greg has used Carer Gateway and finds it a useful service to help carers navigate through the information and services they can access.

In particular Greg has found the videos featured on the website a great help. The content about carers looking after themselves has also been very valuable to Greg.

'I think it's really important that carers are more proactive with their own health and wellbeing. I have definitely taken that information on board.'

You can contact Carer Gateway at www.carergateway.gov.au or on 1800 422 737 between 8am and 6pm.

Graduate Certificate in Autism

University of Wollongong have a new Graduate Certificate in Autism Graduate Certificate in Autism is beginning in 2017. It is led by Doctor Amanda Webster and Doctor Rose Dixon.

This course is not just for teachers, but for anyone that would like to learn more about Autism Spectrum Disorder. This course is useful for parents, carers, TAFE students, Occupational Therapists, Speech Pathologists, Psychologists, Social Workers and many more people in the community.

More information is at <http://coursefinder.uow.edu.au/information/index.html?course=graduate-certificatein-autism-online-course> or email Ali Fitzgerald on afitzger@uow.edu.au.

NSW Industry Innovation Awards nominations now open

Nominations are now open for the 2017 NSW Disability Industry Innovation Awards! The awards seek to recognise and reward excellence and innovation demonstrated by individuals and organisations making a difference to the lives of people with disability, their families and carers.

Innovation is critically important in the context of the NDIS roll out, and the awards are a showcase of the interesting and important work done by providers at this vital time.

The purpose of these awards is to celebrate outstanding achievements made by non-government, community-based organisations and individuals working in the industry.

This year, there are eight categories in the awards including Leadership in community accessibility and inclusion, Excellence in person-centred service provision, Leadership in employment inclusion and Innovation in improving outcomes for children and young people.

All finalists and winners will be recognised at a ceremony as part of the NDS NSW Conference on 23 February 2017. Nominations close 5pm on Monday 21 November 2016.

For more information go to www.disabilityawards.com.au.

Australian Govt. will push IT vendors to make products disability-friendly

The Australian government has put technology vendors on notice to make their software more accessible for public servants with disabilities. John Sheridan, the Australian government's chief technology officer, has revealed that the Commonwealth is poised to launch a public consultation process in order to bring its ICT procurement standards for accessibility into line with European and US standards.

He said that the federal government planned to directly adopt the text of the European standard after what he anticipated to be a short and painless public consultation process. He said he hoped that the Australian standard would be in place by the end of the year.

Having a Say Conference

VALID Presents the 18th Annual Having a Say Conference. Held at Deakin University, Waterfront Campus, Geelong from 8th – 10th February, 2017.

Australia's largest conference for people with disability The Having a Say conference is a place where people can speak up and have their voice heard, be respected and empowered and it's a lot of fun!

Features include:

- Presentations and performances by people with disability
- Workshops and information sessions
- Dinner Disco
- Red Faces Talent Show

Early Bird registration are due by 25th November 2016.

A reduced fee is available to staff, parents or carers who are only attending to provide assistance (e.g.. transport, personal care, supervision).

For more information go to www.valid.org.au.

Australia's educational policies both embody and entrench low expectations of students

It was George W Bush who first described low educational expectations as a form of "soft" bigotry. But it is a mantra that has held a lot of appeal for Australian politicians and educational bureaucrats.

Sometimes the finger is pointed at teachers who are accused of not setting high enough standards for some of their students. Sometimes the blame is assigned to the low achievers themselves. They don't expect enough of themselves, or their parents don't or their communities don't.

But it seems politicians and bureaucrats are blind to their own bigotry, most particularly the ways in which their educational policies both embody and entrench low expectations of students with disabilities, and those who speak English as an additional language or dialect (EALD).

Who needs a teacher, when caring will do.

The federal Department of Education website is unequivocal about the importance of teachers.

The first step to achieving a quality education, which is so critical for the future of young Australians and our nation, is to lift the quality, professionalisation and status of the teaching profession.

Except, that is, for those with special needs or those learning English. They just need some caring companions.

Expectations of students with disabilities and newly arrived English language learners are so low that educational policies do not require they are taught by qualified specialists.

South Australian politician Kelly Vincent calls out the culture of low expectations in the area of disability

education.

Support for students with special needs in most mainstream classrooms consists of a caring, but unqualified, teaching assistant sitting with a student for an hour or two a day.

UK research has revealed that this model of educational support for disability actually results in poorer educational outcomes for the students. As shocking as that sounds, it isn't really surprising.

Low expectations of these students means they are very often just kept busy with what they can do, rather than what they could do with the support of a qualified teacher.

Low expectations come with a high price tag. We spend A\$3 billion employing unqualified teaching assistants to provide pleasant but apparently ineffectual company to students with special needs.

Up to Half of People Killed by Police Have Disabilities

In late September, police in El Cajon, California, shot and killed 30-year-old Alfred Olango after his sister called 911 for medical assistance because her brother was suffering a seizure. Police say Alfred was acting erratically, but his sister says he was mentally disabled and had just had a seizure. Unarmed and in need of help, Alfred is not alone.

As of July, police had killed at least 800 Americans in 2016, many of whom were people of colour, disabled, or had a mental health condition according to Thinkprogress.org. These shootings ignited Black Lives Matter protesters across the country and sparked a desperate plea to officers quick to draw a gun. Alfred is not the only disabled person to be killed by police. A report released by the Ruderman Family Foundation says people who are disabled or have mental health conditions make up nearly half of all people killed by police. With the African-American community more likely to experience severe mental illness because of lack of treatment and other barriers, these people are particularly vulnerable to police violence.

As we all try to make sense of such senseless violence, here's what you need to know about Alfred Olango,

and what his death says about mental health and law enforcement.

What does a seizure look like?

Alfred's sister said her brother was having a seizure when she called police asking for help, but police say Alfred was walking erratically in traffic and took something out of his pants pocket. From everything we see about seizures on TV or in movies, it might seem like it's not possible for Alfred to have been having a seizure while doing all those things, but that's actually not true. There are a bunch of different forms seizures can take.

According to the Centres for Disease Control, seizures can include the typical things we hear about like falling down, shaking, and loss of consciousness, but they can also be less noticeable. Symptoms of a seizure can also include rapid blinking, staring into space, confusion, and the temporary inability to respond to questions or take direction.

Seizures are caused by much more than epilepsy. Certain medications, head injuries, internal bleeding, low blood sugar, stroke, and much more can all result in seizures. People with autism are also likely to have seizures,

with around one-third of all people with autism experiencing seizures according to Autism Speaks.

What does disability have to do with it?

To be clear, having seizures is not a mental disability or illness, it's a neurological condition. But, Alfred's sister did say he had a mental disability. If that's the case – the details are still emerging – Alfred is yet another disabled person killed by police. The Ruderman Family Foundation report found one-third to one-half of all people killed by police have some sort of disability and according to The New York Times, 25% or more of people in police shootings have a mental disorder. That, as NBC points out, has drawn increasing attention to how law enforcement handles mental health and wellness, a part of a police officer's job that has been growing over the years. In San Diego, 911 calls involving mental health grew 84% over the six years from 2009 to 2015, according a San Diego Association of Governments study.

For the rest of the article go to www.teenvogue.com/story/half-of-peoplekilled-by-police-have-disabilities.

Carers Day Out

Carers NSW are celebrating their 40th Birthday celebrations with an Expo for Carers from 10am to 2pm on Wednesday 26 October at the Dapto Ribbonwood Centre.

It is an Expo for people who care for a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

The event will be a day dedicated to relaxation and wellness and will include interactive workshops, complimentary massages and mini facials and a delicious lunch.

There will also be local service providers to meet with carers on the day and provide information and advice.

For more information go to www.carersnsw.org.au/celebrating40years.

11 Children's Books That Help Kids Understand Learning Disabilities

Physical disabilities may hinder a person's ability to accomplish something, but a learning disability can often be equally frustrating, especially for children. Without any physical symptoms or changes, kids often feel insecure and embarrassed by their learning disabilities. For children who don't have any, they may also find themselves conflicted about a peer who has difficulty reading or the kid who's always getting in trouble because they can't focus.

Educational books can do a lot for understanding, but it's important to have children's books that help kids understand learning disabilities so they can connect with characters just like them.

According to the Learning Disabilities Association of Georgia, a learning disability is a neurological disorder that affects one or more of the basic psychological processes pertaining to writing or reading. The LDA of Georgia also noted that most people with learning disabilities are of average or above average intelligence.

For the rest of the article go to www.romper.com/p/11-childrens-booksthat-help-kids-understand-learningdisabilities-17661.

Dystonia Network Of Australia

Dystonia is a neurological movement disorder that makes it difficult for people to control their muscles. It can cause abnormal twisting or positions in part(s) of the body along with muscle spasms or tremors. In some people the postures may be fixed or locked in position and in others pain can be the main symptom.

Dystonia can affect almost any part of the body. There are many forms of dystonia and many conditions or diseases that include dystonia as part of the symptoms.

Dystonia Network of Australia Inc.

(DNA) is a national association and charity which has its origins in the Blue Mountains. DNA aims to provide appropriate, researched information for adults and children with dystonia, their carers and interested health providers to increase community awareness of the condition and ultimately fund seminars and assist with research into dystonia.

They also have a support group that meets every two months. For more information, contact Kerrie Jackson, President on 4784 3368 or email info@dystonia.org.au, or website www.dystonia.org.au.

Riding The Wave

Families of children with disabilities are being encouraged to join in the fun of the beach and Surf Life Savings Nippers program through the Illawarra Branch's Riding the Wave Nippers program. This program provides the opportunity through the clubs for children of all abilities to participate in beach and water-based activities such as beach ball games, board surfing, ocean wading and beach sprints.

Get involved and have some fun! The Riding the Wave initiative is a joint program between Illawarra Surf Life Saving Clubs, Surf Life Saving Illawarra Branch, the Office of Sport and Recreation, CatholicCare and The Disability Trust.

Riding the wave is an eight-week

program. Enrol for all eight-weeks or either of the 4 week blocks. Enrolments close date Wednesday 2 November 2016

When: Every Sunday morning 20 November till 11 December 2016 and 29 January till 26 February 2017

Local clubs and times - Towradgi - 11:00am – 12:00pm, Bellambi 11:30am – 12:30pm, Woonona 11:00am – 12:00pm, Bulli 10:45am – 11:45am, Coledale 10:30am – 11:30am

Cost: FREE

For further information and to enrol please contact the Wollongong office of NSW Sport and Recreation on 4228 5355 or email wollongong@sport.nsw.gov.au.

Ables Nightclub - Traffic Light Party



Don't wait until Valentine's Day to try and meet someone, get your dancing shoes on and come party at Ables Traffic Light Party.

Get ready to mingle, especially if you're single and rock up in your preferred colour choice to represent your status... Green means Single and ready to mingle, Amber means Maybe and we can chat, and Red means Taken but here to party. Dress in your colour or grab a coloured arm

band from the staff on the night. So show your true colours at our huge Ables Traffic Light Party from 7.30pm on Friday 28 October at The Ivory (77 Crown st, Wollongong).

Bring your friends along for an awesome night filled with fun and laughter. Who knows... you might even meet that someone special.

Tickets are \$10 from www.trybooking.com/NGZS before Wed 26th October or \$12 at the door. More information is at www.facebook.com/AblesWollongong.



No carer as Lezz died at home alone

The family of a disabled man who died after slipping out of his wheelchair and suffocating on the night a carer failed to go to his house as scheduled say they are haunted by his final hours.

Leslie Troy Ovens, 32, was diagnosed with Friedreich's ataxia at age nine. The disease causes progressive damage to the nerves and led to Mr Ovens being confined to a wheelchair in his midteens.

Mr Ovens had lived independently in his Ellenbrook home for years with the help of carers who visited morning and night.

The carers were provided by private operator Cam Can, under a service

agreement with the Disability Services Commission.

But in July 2013, a scheduled Wednesday night visit from a carer did not happen and Mr Ovens was alone when he fell out of his motorised chair. He was found dead the next day.

An inquest is being held into Mr Ovens' death to determine how he died, and whether the presence of a carer would have made any difference.

His stepfather Phil Townsend said that despite his disability, "Lezz" Ovens loved life.

Carer Tony McCabe, who had called in to see Mr Ovens on a social visit on the night he died, told Deputy Coroner

Evelyn Vicker that his friend had no idea which carer was scheduled to see him later. "I said, 'Somebody will be coming, don't worry,'" Mr McCabe told the Coroner's Court.

But no one did.

The inquest was told about confusion over rostering of carers, with regular Cam Can care co-ordinator Clare Allen on holiday until days before Mr Ovens' death. A roster schedule sent out for the week of Mr Ovens' death had been blank for the Wednesday night shift, the inquest was told.

"It tells me that there was not a clear (rostering) system in place," Ms Vicker said.

Illawarra Disability Alliance fighting for lifts at Unanderra station

Sixteen disability service providers have joined forces to push for better access to Unanderra station.

Since early last year the Unanderra Access Group (UAG) has been tirelessly lobbying the NSW government to improve access to the station.

The island platform is only accessible by two sets of stairs, each of which has more than 30 separate steps.

At a meeting with Transport for NSW officials in September, UAG representatives were told an accessibility upgrade "will be carefully considered as part of the program's ongoing prioritisation process."

Now the Illawarra Disability Alliance has joined the fight. The group includes Greenacres Disability Services, Flagstaff Group and The Disability Trust and their plan is to push for more immediate access rather than waiting for lifts.

"We find it appalling that in 2016, people with disability cannot safely access one of the busiest train stations in Wollongong," Flagstaff Group CEO Roy Rogers said.

"They should open up Berkeley Road to pedestrian access – like Nolan Street Unanderra – which would eliminate the stairs issue. People could then access the station via a ramp.

Greenacres CEO Chris Christodolou felt it was only a "matter of time" before someone injured themselves on the stairs.

"It is not only people in wheelchairs that have to cope with hundreds of steps but also parents with prams, the elderly and those commuters with poor mobility," Mr Christodolou said.

"We believe that the upgrade of Unanderra station is beyond politics and, like the National Disability Insurance Scheme, should receive bipartisan support."

Disability Trust CEO Margaret Bowen said the group was aiming to meet with Transport minister Andrew Constance and Disability Services minister John Ajaka to discuss short and long-term options for the station.

Let's Try Wheelchair Sports

People with physical disabilities, their families and friends are invited to come and try Wheelchair Sports. The afternoon will involve a rotation between tennis, basketball and badminton. This is a perfect opportunity for you to try something new and meet representatives from Spinal Cord Injuries Australia and Wheelchair Sports NSW. It will be held at the Shellharbour City Stadium, 272 Croome Road, Albion Park from 2pm to 4pm on Saturday 12 November 2016. Contact Mel Gorman on 4225 1366 or at mgorman@scia.org.au for more information.

Making New Year's Eve more accessible in Wollongong

New Year's Eve celebrations in Wollongong will include some new features to help people with a disability enjoy the festivities.

Wollongong City Council's Acorn Lawyers' New Year's Eve will trial a reserved seating area for people with a disability in front of the shared footpath along Belmore Basin. The area is adjacent to the Harbourfront Restaurant and will include an accessible drop off and pick up zone.

Due to the limited number of places available, Council is requesting people with a disability secure their place in advance by booking online at www.wollongong.nsw.gov.au/nye. Groups of more than six people need to contact the Event Manager on 4227 7104 or email phorner@wollongong.nsw.gov.au to secure their booking.

Council has also increased the number of accessible parking spaces along Endeavour Drive, however, these will not be reserved. You must have a valid Mobility Parking Scheme permit to park in these spaces and they will be available on a first in, first served basis.

If you have a mini bus with a valid Mobility Parking Scheme permit and you require parking please contact the Event Manager 4227 7104 or email phorner@wollongong.nsw.gov.au.

For more information you can contact Council's Customer Service on (02) 4227 7111 or visit their website at www.wollongong.nsw.gov.au.

Davidson Deaths: Maria Lutz Friends Pay Tribute to 'Amazing Mother' Found Dead with Family in Murder Suicide

A woman found dead alongside her family in a Sydney murder-suicide case was a fighter and an amazing mother, say friends who she worked with at a school for children with disabilities.

Maria Claudia Lutz, her husband Fernando Manrique and their two children, Elisa, 11, and Martin, 10, who both had autism, were found dead in their home in the northern Sydney suburb of Davidson on Monday.

Police say they were gassed in an apparent murder-suicide.

Karen Hickmott is one of half a dozen women who knew Maria Claudia Lutz through St Lucy's primary school in Wahroonga.

"She was always caring about everyone else, it didn't matter what was happening in her life, she was always most worried about everyone else," Ms Hickmott told 7.30.

"She never let any of her troubles show, she was a fighter and she was tough."

So it was a surprise to them all when Ms Lutz didn't turn up for her regular canteen duty on Monday morning.

"Maria and I ran the canteen together, every Monday, for the last two years, and she was always here before me," Nichole Brimble told 7.30.

"When I turned up and she wasn't here, I knew something was wrong. And the kids weren't here.

"When we couldn't make contact, we made the call to police to ask them to go and check on them.

"Then we found out, the principal called me into his office about 12 o'clock to let me know what happened."

'Maria was the glue for this group'

There had been nothing in Ms Lutz's behaviour that gave an indication that anything was wrong.

"We'd all been out for coffee on Friday



and we all sat in the nursery ... and she was in such good spirits," Peta Rostirola remembered.

"She was Maria, she was loud and funny and she was so happy her life was going in the right direction.

"She'd had a meeting with the NDIS and she was so excited she was going to be getting all this help.

"She even felt guilty for taking that, she was just the most selfless person."

For the rest of the article go to www.abc.net.au/news/2016-10-18/st-lucy-school-mothers-remember-maria-claudia-lutz/7944036. If you or anyone you know needs help contact Lifeline on 13 11 14.

Trusted Travel



Trusted Travel offer holiday packages for groups, families or individuals living with a disability that may require extra support planning that dream holiday or weekend getaway.

Melissa had never been to Melbourne before and it was her first time away her friends.

Melissa was part of the recent group holiday experience "Explore Melbourne".

Supported by Trusted Travel's fabulous guide Megan, the group enjoyed 4 days of site seeing, shopping, eating out and fun activities like checking out the amazing Melbourne Aquarium, taking in the views from the Eureka Sky Deck 88, shopping at the Queen Victorian Markets, going along to Etihad Stadium for a blockbusting AFL match and more!

Everyone had an awesome time!

Unlike some travel services, Trusted Travel's holiday packages can include absolutely everything! Transport, accommodation, meals, activities and support staff can all be arranged by trusted Travel.

The group holidays are a great way to share experiences and meet new friends. Or if there is somewhere special you have dreamt of going, they can customize your itinerary to suit you!

All support needs are considered and they will ensure your itinerary is individualised to your needs.

Trusted Travel is part of The Disability Trust. For more information email info@trustedtravel.org.au or call 4255 3100.



Experienced · Reliable · Fun

Addison's Big Chop

Addison is only 6 years old and already has a heart of gold. She has been asking to cut her hair for well over a year now but I kept pushing it aside. The last time she asked I said maybe, but, I really love your beautiful hair.

That's when she said "Mum I can give it to a little girl in hospital, so she has hair again".

My heart almost burst with pride.

So I started to research on how we go about donating her hair. The biggest shock to me was learning that just 1 wig can cost up to \$6,000 with the average wig costing \$2,000 to \$3,000 and will only last 2 - 3 years. A cost that many families just like mine would struggle to cover. Variety use all money raised to buy wigs and gift them to children who have lost their hair through a medical condition.

If you have any spare \$\$\$, big or small, we would really appreciate your support. You can donate by going to <https://alopecia.everydayhero.com/au/Addison>.

Addison's big chop is set for November 5th 2016.

NDIS: Half signed getting disability support for first time

Glance once at Teisha Rose; you'll see a dark-haired woman walking alongside the glossy, silvered expanse of the bay, a little terrier on a lead.

Look twice, and you might notice the slim black cane she uses for support on longer walks, or when she's having a tough day.

Twenty years ago, Rose was diagnosed with multiple sclerosis, a condition of the central nervous system that interferes with nerve impulses. During her relapses Rose has been bedridden in hospital, or in a wheelchair, with little mobility.

But aside from a short stint on the disability pension as a student years ago, Rose did not receive any disability support until the National Disability Insurance Scheme (NDIS) trial started in her area in 2014.

This was because she wanted to work – not possible on a pension – and because her diagnosis “fell between the cracks”.

“With MS you slip between two worlds; you are either in the world of hospital and rehab, or you do everything you can to get better and

are too ‘well’ to qualify,” Rose says.

Half of the people now signed up to the NDIS are getting disability support for the first time; evidence of the huge demand for disability services across Australia, a new report shows.

And “autism and related disorders” are the most common disability type, representing about 30 per cent of participants across Australia, the National Disability Insurance Agency's quarterly report reveals.

The previous disability system was a crisis-driven, “band-aid” approach, where people had to fight for funding says Braedan Hogan, the policy manager at autism advocacy organisation Amaze.

Many children with autism did not qualify for support. But it became obvious when they reached school that they really needed interventions like speech pathology, he says.

About 2.4 billion has been committed to fund the 35,600 people on the NDIS scheme so far. One in 10 people has a support package worth more than \$100,000, while 70 per cent have a package below \$30,000.

After her diagnosis at 22, Rose spent years trying to forge ahead in her corporate career. But each relapse shook her confidence, and after a long hospitalisation she opted to change pace and moved to Bendigo to study social work.

These days she lives in St Leonards and works part-time for her father's marketing consultancy. She has written a book, blogs and runs a website about living with her disability and the importance of inclusive workplaces.

While doing research on the NDIS for a work client, she realised she might qualify herself.

Her package includes visits to a neurophysiotherapist and support from a cleaner. This has allowed her to work and avoid gruelling hospital visits.

The NDIS has been plagued by computer bumbles that have affected payments and plan approvals; Rose is still not able to get online to check how many physio sessions she has left. But it's still better than her experience of the disability pension.

New resources available to help people with disability move to the NDIS

New resources have been developed to support a greater understanding of key concepts such as the first planning process and how people with disability will continue to receive quality supports as well as clarity around common terms within the NDIS.

My first plan fact sheet: (www.ndis.nsw.gov.au/ndis-resources/fact-sheets/factsheet-my-first-plan): information on the first plan process in plain English and easy read English. These fact sheets provide information about what to expect and how to prepare for a first plan meeting.

The Easy English my first plan fact sheet (www.ndis.nsw.gov.au/wpcontent/uploads/2015/11/Factsheet_My_first_plan.pdf) uses images as well as text to illustrate the first plan process.

NDIS Word list (www.ndis.nsw.gov.au/wp-content/uploads/2015/11/NDIS_Glossary_ER_ACCESSIBLE.pdf): there are a lot of new terms to understand as

people transition to the new scheme, so we have developed an Easy Read word list to help explain the NDIS.

Providing quality and safe supports for NDIS participants in NSW (www.ndis.nsw.gov.au/ndis-resources/factsheets/providing-quality-and-safesupports-for-ndis-participants-in-nsw).

This fact sheet details how people with disability will continue to receive quality and safe supports during the transition to the NDIS between 1 July 2016 and 30 June 2018.

Our fact sheet on The NDIS for people aged 65 (www.ndis.nsw.gov.au/ndisresources/fact-sheets/fact-sheet-thendis-for-people-aged-65-and-over) has also been updated with new information on the next steps and who can be contacted for more information.

For more information and to access the latest information sheets visit the NSW NDIS website resources page (www.ndis.nsw.gov.au/ndis-resources).

NDIS Portal Problems Resolved

The breakdown of the new MyPlace NDIS portal after the start of the full NDIS rollout has now been fixed.

However, it caused major problems for many service providers, people with disability and their families and carers.

A Pricewaterhouse Coopers report found that the IT system was not ready to go and should not have been activated so quickly. It has also been reported that the glitch has meant only a fraction of the anticipated 20,000 plans have been completed nationwide in the first three months of the full scheme.



...creating an inclusive world

NDIS Update



Are you NDIS Ready?

The National Disability Insurance Scheme or NDIS is the biggest change to the way people with disability are supported in Australia's history. If you would like to know more about the NDIS call The Disability Trust on 1300 DISABILITY (1300 347 224) or at info@disabilitytrust.org.au.

Corporate Heavyweights Replace Bonyhady in NDIS Shakeup

The so-called "father" of the National Disability Insurance Scheme, Bruce Bonyhady, is set to be replaced in an agency clean up, according to reports.

An article published in The Australian on in mid-October, claimed Minister for Social Services Christian Porter was finalising a list of "corporate heavyweights" to replace the current board in a purge of management.

The claims were based on leaked letters seen by the news organisation which showed a list of new appointees including Helen Nugent, the chairwoman of credit reference outfit Veda Group, who is tipped to replace Bonyhady as chair at the start of 2017.

The Australian quoted a letter from

Porter to the states and territories that said: "Should we not be able to reach agreement on any of these appointments, I intend to exercise my powers to appoint the nominees in the above final list after 90 days from the date of this letter (September 30) to ensure there is a fully functioning, high-quality board in place from 1 January 2017."

Porter declined to comment on the specifics of the leaked letters but told Pro Bono Australia News there had been a consultation process for board appointments.

For the rest of the article go to <https://probonoaustralia.com.au/news/2016/10/corporateheavyweights-replace-bonyhady-ndisshakeup>.

NDIS – on time and on budget

The NDIS Quarterly Report for April-June 2016 - the last of the three-year trial period - has been released showing:

3519 registered service providers

50 per cent of active participants received disability services for the first

time

The largest amounts overall - \$577 million - has been paid for assistance with daily life at home, in the community, education and at work.

See the graphic below for more information from the report. Read

New NDIA Guidelines

The NDIA has updated its Operational Guidelines that outline how they make decisions.

The updated guidelines consolidate 69 separate guidelines into a resource divided into 10 parts. The guidelines can be found at www.ndis.gov.au/operational-guideline/overview.html.



Quarter 4, 2015–16 Report

30 JUNE 2016

NDIS trial sites



On time

35,695 people

have become participants in the NDIS.

30,281 people

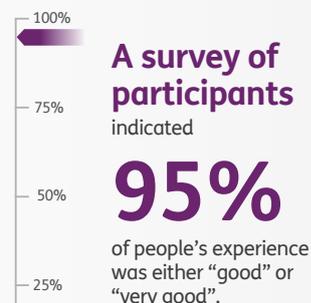
have received individualised plans, helping them change their lives by accessing the supports and services they need to live more independently and engage with their community.

Within budget

\$2.4b

has been committed for participant support to date.

High satisfaction



Participants with approved plans by state and territory

| NSW Hunter | NSW Nepean Blue Mountains | SA | TAS | VIC | ACT | NT | WA | QLD |
|------------|---------------------------|-------|-------|-------|-------|-----|-------|-----|
| 7,805 | 1,804 | 7,118 | 1,162 | 5,284 | 4,098 | 155 | 2,494 | 361 |

NDIS is having a powerful impact

An article by Alastair McEwin, the Australian disability discrimination commissioner. Getting a morning coffee on the way to work is a ritual many of us take for granted. Not Jeremy, who is a young man with a communication disability.

The thought of not only being able to order coffee, but run a business, was a pipe dream. Until the National Disability Insurance Scheme arrived in Lake Macquarie.

Jeremy had the opportunity to start communicating for the first time with an iPad app. He now does a local coffee run where he takes coffee orders from local business people, fulfils them and makes the deliveries. And six months ago he was unable to communicate with the wider community.

The NDIS is a major social reform in Australia. The last time we saw something on a similar scale was the introduction of universal health care for all Australians in 1975 – Medicare.

The introduction of Medicare was not

without its challenges, but universal healthcare is now considered a fundamental and essential part of our lives.

The NDIS is about ensuring people with disability can get out and about in the community – it's about getting them to work, to school and to cafes and restaurants so they can catch up with family and friends. It's about getting people with disability being able to be part of the workforce, getting an education and spending money on food and drinks – in other words, being part of the economic, social and cultural fabric of our lives.

It isn't just making life equitable for people with disability. It's also making it possible for them to participate in every-day life with their families. In the Hunter region, a family has used the NDIS package to take a support worker for their family member with disability with them on family holidays. This gives real meaning to the term "family holiday" – it's hardly that if the person with disability cannot go away with their family.

And the NDIS is even allowing parents of children with disability to work full-time. One family, through the NDIS, now has support after school and during the school holidays for their daughter with disability, which allows both parents to keep working full-time; in doing so, they are able to contribute to the economy through paid employment and paying taxes.

And their daughter gets to spend her holidays doing things she loves like hydro therapy. Given its scale, there will be implementation issues for the NDIS.

There will be challenges in rolling this out across the country. And there will be doubts. Yet we have had other massive social reforms that are now so embedded in our society that we cannot imagine life without them (the conversion in 1966 from metric to decimal anyone?). The NDIS needs to be seen in this light – it needs time to become a part of our lives and, more importantly, to provide the equity of access to people with disability that has been denied to them for so long.

NDIS accused of blocking ACT participants despite being uncapped

The National Disability Insurance Scheme (NDIS) is being accused of blocking people from taking part in the program, despite it being uncapped.

The ACT Government said the Commonwealth agency rolling out the NDIS had told people in Canberra with disabilities it would not meet with them. It was originally estimated 5,075 people in the territory would eventually be eligible for the scheme. That number has already been reached.

It appears the National Disability Insurance Agency (NDIA) recently

told individuals or groups no new planning meetings would be taking place — something that would be unprecedented under the unlimited program.

It is unclear how many people were affected.

Director-general of the ACT Community Services Directorate Michael De'Ath said "it was recently brought to the attention of the Community Services Directorate that the NDIA was advising clients that no new planning meetings will be undertaken in the ACT".

The Federal Government and NDIA have not denied such a directive went out. The entire ACT was a trial site for the NDIS, which is now being set up nationwide and is soon set to cost \$22 billion annually.

A fight is now brewing between the two governments about which pays for the extra participants.

"The ACT NDIS bilateral agreement outlines a target of 5,075 ACT participants, with the clear understanding that the Commonwealth Government accepts the full cost for any participants beyond this figure," Mr De'Ath said.

Market Position Statement for ACT & Southern NSW

The NDIA has released a Market Position Statement (MPS) for ACT and Southern NSW. The MPS provides information on the emerging marketplace. It allows providers to better understand areas of expected demand growth and plan their services. You can access the Market Position Statement at www.ndis.gov.au/marketposition-statements.html.

Project supports adult Siblings

Creating Capacity: Support for Adult Siblings is a project that aims to build the capacity of adult siblings of people with disability to understand the role of the NDIS and support their brothers or sisters in the NDIS.

Go to <http://siblingsaustralia.org.au/adultsibs.php> for more information.

NDIS website address Changed

The NDIA has changed the domain name of its website from www.myplace.ndis.gov.au back to www.ndis.gov.au.

Should the links you are currently using not work, please remove 'myplace' from the domain name or use the search function on the home page.

For Your Calendar. . .

10th International Brain Tumour Awareness Week –22 to 29 October

The Brain Tumour Alliance Australia encourages you to organise an activity which will contribute to increased awareness about brain tumours.

Pink Ribbon Day - Cancer Council – 24 October

Cancer Council's Pink Ribbon Day helps raise funds in support of the many thousands of Australian women affected by breast and gynaecological cancers. For more go to www.pinkribbon.com.au.

National Bandanna Day - CanTeen – 28 October

National Bandanna Day is CanTeen's major fundraising and awareness campaign to support young people affected by cancer. More at www.canteen.org.au/bandanna-day.

SUDEP Awareness Day – 23 October

SUDEP stands for Sudden Unexpected Death in Epilepsy. Go to www.sudepglobalconversation.com for more.

November

Movember – 1 to 30 November

For 30 days, champion the moustache and raise funds for men's health, more at <https://au.movember.com>.

Lung Health Awareness Month – 1 to 30 November

During November we celebrate the importance of breathing and encourage everyone to stop and think about what they can do with just one breath. More at <http://lungfoundation.com.au/events/lung-health-awareness-month>.

National Walk to Work Day – 7 October

An annual event which helps employers and employees to build regular walking into their daily routine. More at www.walk.com.au/wtw/homepage.asp.

Perinatal Depression and Anxiety (PANDA) Awareness Week – 13 to 19 November

The Week aims to raise awareness about perinatal depression and anxiety, including the signs to look for and where to go to seek support. More information at www.panda.org.au/get-involved/panda-events/pnda-awareness-week.

World Diabetes Day – 14 November

World Diabetes Day is an international event to raise awareness about diabetes, celebrated every year on 14 November. The theme of World Diabetes Day 2016 is Eyes on Diabetes. More at www.diabetesaustralia.com.au/world-diabetesday.

White Cane Day –

The mission of White Cane Day is to educate the world about blindness and how the blind and visually impaired can live and work independently while giving back to their communities, to celebrate the abilities and successes achieved by blind people in a sighted world and to honour the many contributions being made by the blind and visually impaired. More at www.whitecanneday.org.

World COPD Day – 16 November

Get involved in World COPD Day to raise awareness about the symptoms, risk factors and treatment for Chronic Obstructive Pulmonary Disease (COPD). More at <http://worldcopdday.lungfoundation.com.au>.

DonateLife Thank You Day – 20 November

DonateLife Thank You Day is a national day to honour all living and deceased organ and tissue donors and their families and to acknowledge their generosity, which saves and transforms the lives of others. More at www.donatelife.gov.au/thank-youday.

Assistance Dogs Australia Awareness Week – 20 to 26 November

Australia goes to the dogs in November for Assistance Dogs Awareness Week, celebrating the work of all of Assistance Dogs Australia's doggooders. More at www.assistedogs.org.au/news.php/18/assistance-dogs-awareness-week.