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Self-injurious behaviour in Cornelia de Lange syndrome: 1. Prevalence and phenomenology

**Background**  Self-injurious behaviour is frequently identified as part of the behavioural phenotype of Cornelia de Lange syndrome (CdLS). We conducted a case-control study of the prevalence and phenomenology of self-injurious behaviour (SIB) in CdLS.

**Methods**  A total of 54 participants with CdLS were compared with 46 individuals who were comparable on key variables including age, degree of intellectual disability and wheelchair use, using questionnaire and observational measures.

**Results**  Clinically significant self-injury was not more prevalent in the CdLS group (55.6%), nor was it different in presentation from that seen in the comparison group. Hyperactivity, stereotyped and compulsive behaviours predicted clinically significant self-injury in all participants. Hand directed, mild self-injury was more prevalent in CdLS.

**Conclusions**  The results show that clinically significant self-injury may not be part of the behavioural phenotype of CdLS but a specific body target for proto-SIB is more common.

Self-injurious behaviour in Cornelia de Lange syndrome: 2. association with environmental events
Journal of Intellectual Disability Research, Volume 53 part seven July 2009, pp.590-603

**Background**  Self-injurious behaviour is commonly seen in Cornelia de Lange syndrome (CdLS). However, there has been limited research into the aetiology of self-injury in CdLS and whether environmental factors influence the behaviour.

**Methods**  We observed the self-injury of 27 individuals with CdLS and 17 participants who did not have CdLS matched for age, gender, level of intellectual disability and mobility. Descriptive analyses were used to determine the extent to which environmental events were associated with self-injury.

**Results**  Lag sequential analysis of the association between self-injurious behaviour and environmental events revealed no differences between the two groups in terms of either the number or degree of environmental associations.

**Conclusions**  The results suggest that the associations between the environment and self-injury in CdLS do not differ from those seen in the broader population of people with intellectual disability. By implication the social reinforcement hypothesis is equally applicable to both groups.

Staff variables associated with the challenging behaviour of clients with severe or profound intellectual disabilities

**Background**  Previous research has identified that staff–client interactions play an important role in the origin and maintenance of challenging behaviour. Particularly, the reciprocity between staff
behaviour and client behaviour has been considered a key issue. Furthermore, severe challenging behaviour has been found to elicit negative emotional reactions from staff which in turn may influence staff’s behaviour. Another variable that has been associated with staff behaviour are staff’s attributions regarding clients’ challenging behaviour. The present study tested several hypotheses about associations between staff variables and challenging behaviour.

**Method**  Questionnaires were used to investigate associations between the attributions, emotional reactions and behavioural reactions of 51 staff members towards challenging behaviour of clients with severe or profound intellectual disabilities who displayed self-injurious behaviour, stereotyped behaviour and/or aggressive/destructive behaviour.

**Results**  Staff members reported that reactions to challenging behaviour differed according to the type of challenging behaviour. Negative emotional reactions were positively associated with challenging behaviour. Associations between emotional reactions, staff beliefs and staff reactions were inconsistent.

**Conclusions**  The findings suggest that there is a need to look for a better conceptualisation and assessment of the variables under investigation.

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**Parents' Perceptions of Postschool Years for Young Adults With Developmental Disabilities**

Intellectual and Developmental Disabilities, Volume 47 Number 3 June 2009, pp.186-196

This qualitative study investigated parents’ perceptions of the various roles they played in their adult children’s lives during the post-high school years. Individual face-to-face interviews were conducted with 9 families of young adults with developmental disabilities. Findings indicated that families perceived the complexity of their roles as balancing between advocating for their adult children’s needs while promoting independence and self-determination. The roles parents assumed as their children entered into adult life were those of collaborators, decision makers, and program evaluators, role models, trainers, mentors and instructors, and systems change agents. Parents often felt they were the safety net for their children and the back-up plan for service agencies. Parents’ quotes illustrated the complexity of the roles they played as their young adult children with developmental disabilities entered adulthood.

**Involvement of Adult Siblings of Persons With Developmental Disabilities in Future Planning**


This study examined factors influencing involvement of siblings of individuals with developmental disabilities in future planning and their expectation of future caregiving. The sample consisted of 139 adult siblings recruited from an online sibling list and a sibling conference. Results indicated that few families made plans or involved siblings in the planning. Siblings who were most involved in future planning were older, more involved in disability activities, and provided more support to their sibling with disabilities. About 38% of siblings expected to be primary caregivers and were more likely to expect this role if the sibling with a disability lived closer and was female, had more sibling contact, provided them with more support, and felt greater caregiving satisfaction. Major support needs of siblings were for support groups, workshops-training on how to assume caregiving responsibilities, financial support, and printed material on making future plans.
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Book review
Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities
Second Edition
Nick Bouras & Geraldine Holt
THE Federal Government should fund children, not schools, if it wants to end the spat between the public and private sectors, a conservative think-tanks says. Under such a system each school age child would be given an education entitlement to fund their education based on individual need, Jennifer Buckingham argues in a paper for the Centre for independent Studies.

"Funding would follow children and schools with the neediest children would receive the most public funding, regardless of the type of school (public or private)," Ms Buckingham writes in In Defence of Non-Government Schools.

"The education entitlement could be weighted so that children whose learning needs are greater would be given more funding."

Children from low socio-economic backgrounds or remote areas might get more money, as would those with a disability or English as a second language.

Ms Buckingham says creating a single funding source and then funding children rather than schools, is the only way to create equity in funding and end the long-running debate that pits sector against sector and shifts blame for problems between different levels of government.

The country's 2700 private schools are currently funded under the controversial socio-economic status (SES) model, introduced by the former Howard Government. It assesses need according to the average wealth of the census district in which students live rather than a private school's actual
resources.

Non-government schools will be funded under the SES model until 2012, while the Rudd Government reviews whether it is sustainable and equitable in the longer term.

Ms Buckingham says in light of the impending review "it is necessary to emphasise the important role non-government schools play in education provision across Australia".

Public funding of private schools gives parents choice and denying that choice "is unjust", she writes.
AN ALP-dominated western Sydney council has lobbied the NSW Government to prevent an Islamic school opening in its area, despite Land and Environment Court approval for the development.

Soon after the court dismissed Bankstown Council's appeal against the school, the council wrote to the Minister for Education, Verity Firth, asking that the Government acquire the Bass Hill site, either by agreement or compulsorily.

This week Ms Firth ordered the Education Department to negotiate to buy the site but denied the council's letter played a part in her decision. The land was now needed for a school for disabled children, she said.

Al Amanah College's plans for a 1200-pupil school had been bitterly opposed by the council and residents. Objections were raised on traffic, noise and design grounds, but there were allegations some opposition was racially based.

The council rejected development applications twice, but twice the Land and Environment Court found in the school's favour. The first time, in December, Senior Commissioner John Roseth asked "whether the council would have raised quite as many contentions as it did if the application had been for an Anglican school".

After the second judgment, in May, Al Amanah started preparing to begin building on the site next to Bass High School. Instead, it is now preparing to battle the Government. Ms Firth said in a statement that demand for a special needs facility had been increasing since 2005. But
in 2006 the department deemed the site surplus to its needs and sold it to Al Amanah for $4.4 million.

Ms Firth rejected suggestions that her real purpose was to stop the Islamic school. "This decision was made following advice from the Department of Education and Training that a special school was required in the area and that this was the most appropriate site. It is unrelated to the building of an Islamic school on the site," her spokeswoman said.

If the owners refuse to sell, Ms Firth is prepared to use compulsory-acquisition-of-lands legislation.

The president of the Australian Federation of Islamic Councils, Ikebal Patel, said the Government's plan was preposterous. "To know that there is a school that has gone through two lots of hurdles to now want to exercise compulsory land powers - it's very disappointing."
CONSUMER advocacy group Choice has defended Telstra's new fee for customers who pay their bills in person, saying its common practice for other telcos.

Telstra yesterday introduced a range of steep fees in an attempt to herd its customers into making online BPAY payments and to eliminate costly face-to-face customer service, *The Daily Telegraph* reports.

"They're seeking to migrate us from the old ways ... of walking into a shop with cash and handing it over and stamping the bill, to newer, more efficient ways," Choice spokesman Christopher Zinn said.

"That's not unreasonable, as long as there is scope for people to change.

"Telstra will have to help educate people to avoid the fee, but this is a symptom of what's going on more widely because of the proliferation of billing payment systems."

As many readers have pointed out in the comments section of this story, Telstra is not alone in charging customers to pay their bills.

Vodafone charges customers $2 to receive a paper version of their bill, and $1.50 to pay the bill at Australia Post. According to its website, this $1.50 fee is "to help Vodafone cover the costs of processing payments via credit cards and Australian Post."

Meanwhile, Optus charges $2.20 fee to receive a paper invoice and 55 cents to pay the bill at an Australia Post.

**Telstra's tactic to "save hundreds of millions"**

Telstra's tactic will cost as much as 2 per cent of every bill and is set to save
it "several hundred million dollars" a year. __From September 14, Telstra will charge a $2.20 administration fee for bills paid by mail or in person at a Telstra Shop or Australia Post.

The telco's existing credit card payment processing fee will also rise to 1 per cent of the payment amount for MasterCard, VISA, and American Express cards, and 2 per cent for Diners Club. However, so as not to penalise elderly customers, Telstra will exempt those with a pensioner or disability card from paying the new fees or credit card charges. Telstra Pensioner Discount customers or customers who have already registered their eligible pensioner card details with Telstra for the credit card payment processing fee discount are automatically exempt as are Telstra Disability Equipment Program product customers or those registered for another Telstra Disability Service. All customers who pay their bills through an online savings or cheque account will also be exempt from the fees.
Public servants stood down over respite 'attacks'
24/07/2009
Sydney Morning Herald

Two senior public servants have been stood aside while the NSW disabilities chief and the state's Ombudsman investigate two assaults at a south coast respite centre.

Early on Tuesday morning the severely disabled teenager Meg Makila was bitten in the face and chest by another resident at the Bombaderry Respite Centre.

The 15-year-old, who is immobile, was unable to defend herself against her 22-year-old intellectually disabled male attacker. The pair had been placed in the same facility, in breach of the departmental policy that children and adults be in separate homes.

Despite claims by NSW Department of Disability Services that the attack was an isolated incident, it was reported today that the 22-year-old man had attacked another man at the centre on June 4, and then attempted to strangle a staff member.

The director general of the NSW Department of Ageing, Disability and Home Care, Jim Moore, said two senior public servants had now been stood down over the two attacks.

Mr Moore said he only found out about the June 4 incident on Thursday, while investigating the attack on Ms Makila.

"By the end of the day I had a very different picture of what had gone on in that area and that had led me to take the additional actions of expanding the scope of the inquiries, and to stand aside the two senior managers responsible for respite in that region," Mr Moore told Fairfax Radio Network.

"So I could do my best to give people confidence that we were taking this matter seriously and we wouldn't tolerate circumstances like the ones that we've got in front of us."

Mr Moore also backed staff at the Bombaderry centre, saying he believed they had "done the right thing".

"It's really the overseeing managers who are responsible for making decisions about whether incidents need to be responded to in the right way," he said.

"I've asked them to stand aside, and they will stay out of the management decision making until my inquiries are completed."
Mr Moore said he had already talked to the Deputy Ombudsman about his independent investigation, and welcomed his inquiry into the respite centre.
Disability group pulls ad after tragedy

TORY SHEPHERD, HEALTH REPORTER
July 24, 2009
The Advertiser

A DISABILITY group had an advertisement ready to go warning that it was "only a matter of time before a distraught parent fatally harms their child".

In a terrible coincidence Disability Speaks had planned to place the ad this week, but immediately withdrew it when a mother was accused of killing her disabled, violent son.

Beverley Eitzen cared for her teenage son, who had the mental capacity of a two-year-old and severe "behavioural problems".

Group spokesman David Holst, who has a disabled daughter, has been warning the State Government for five years that under-resourcing and a lack of support for carers would result in tragedy.

"About 80 per cent of carers in the disability sector have mental health issues," he said.

"It has been inevitable for five years and it's going to happen again. People snap under stress . . . it's temporary insanity."

State Government figures obtained by Mr Holst show that hundreds of families are at high risk of harm to themselves or others.

The advertisement shows SA has the lowest average funding per disabled client in the nation.

Minister for Disabilities Jennifer Rankine acknowledged there was still "a big job ahead" to meet the needs for disability services. "There is no doubt we started behind the eight ball, but we have now nearly doubled funding since replacing the Liberals in government," she said.

"We are spending an extra $100m a year, but there is still a big job ahead."

Social Inclusion Commissioner Monsignor David Cappo also says the situation is a "major social disaster". He has first-hand experience as his nephew is autistic. "I'm very, very aware of the stress that families are under and can be placed," he said.

Monsignor Cappo said his unit knew there were "huge gaps" in the system, and recommended trials of "consumer-directed funding" as part of reform in the sector.
"Let's redirect the whole system so it's focussed on giving the parents or carers more power, with direct control over funding packages," he said.
$30,000 after abuse by Catholic brother

Kate Dennehy

July 26, 2009

THE Catholic Church has paid more than $30,000 to a man for sexual abuse he suffered as a child in Queensland and New Zealand 30 years ago.

Darryl Smith, who is mildly intellectually handicapped, said he was abused by brothers of the Hospitaller Order of St John of God (SJOG) in both countries.

In 2003, the Queensland Police Sexual Crimes Investigation Unit received a complaint from Mr Smith saying he had been sexually assaulted by Brother Bede Donnellan, whose real name was John Joseph Donnellan.

Mr Smith, 46, of Mataura in New Zealand said Donnellan had abused him at the Granada Hostel at Ashgrove in Brisbane's west in 1979 when he was aged 15.

Donnellan died before facing possible charges but the Catholic Church's Professional Standards Office in Sydney, in its investigation last year, found that "on the balance of probabilities" Donnellan did sexually assault Mr Smith.

This month Mr Smith received a cheque for $NZ30,000 ($23,150) and had his legal costs covered.

He said last week he had hoped for double that amount but was happy to have the matter settled.

"I had bills to pay and was really sick of it dragging on so I accepted their offer," he said.

He received counselling for two years for post traumatic stress disorder he suffered because of the abuse.
"I consider myself a survivor of abuse now, not a victim," he said.

He was a ward of the state staying at the Queensland Government's Wilson Youth Hospital (later called the Sir Leslie Wilson Youth Detention Centre) at Windsor from 1979, aged from 15 to 19.

Donnellan met Mr Smith at the hospital to access his "suitability" for possible work at the Granada Hostel and he agreed to give him a four-day trial.

Mr Smith said Donnellan sexually abused him in his bedroom on the second night of his stay.

He ran away from the hostel and was found by police at the Gold Coast. Donnellan died in 1995, and the hostel closed in 1985.

Mr Smith was born in New Zealand but his family moved to Beenleigh, south of Brisbane in 1977. He joined them briefly in 1978 but he spent many years in and out of mental institutions, foster care, special needs boarding schools and prison.

He said he was sexually abused by brothers at the SJOG Marylands Special School at Christchurch in New Zealand in 1971 when he was aged seven. The school housed intellectually disabled boys as well as state wards and orphans.

In 2003, he received compensation for that abuse, although his alleged perpetrators were never charged, he said.

Brother Peter Burke of SJOG's Australasian Province apologised to Mr Smith in 2002 when he was in New Zealand's Invercargill Prison serving a nine-year sentence for burglaries, theft and fraud.

The letter said: "On behalf of the Order of St John of God and on my own behalf I offer you a deep and profound apology."

The website of Australian victims' rights group Broken Rites says the SJOG specialised in accommodating boys with educational, behavioural or intellectual disorders. Since 1993 the group had discovered "numerous cases of vulnerable boys and young men
who have been … abused in SJOG institutions". Investigations often were hampered because of the boys' disabilities. "The order has spent huge sums on legal teams to defend particular brothers against prosecution," the site says.

"SJOG has been shamed into paying millions of dollars in civil settlements to many victims in Australia and New Zealand … but there are others who are still entitled to a settlement."

SJOG brothers Bernard Kevin McGrath and Rodger Moloney have been convicted in both countries of child sex crimes.

Mr Smith said he was writing a book about the abuse entitled A Shattered Life.


The Advertiser  
Edition 1 - StateSAT 25 JUL 2009, Page 066  
Support system fails

``LOVING and caring mother accused of the murder of her intellectually disabled son'' (The Advertiser, yesterday). Once again a person with intellectual disabilities loses their life and a loving family is thrown into turmoil because of the failure of the disability support system to operate effectively in South Australia. 

The apparent incapacity of governments of all persuasions to make serious and effective effort in placing support around a person with a disability means we will continue to see such outcomes. 

Other desperate parents will just crumble under the weight of expectation that they will continue to care for their sons/daughters, with little in the way of support, until one or the other dies. 

For people with intellectual disability to have a reasonable quality of life, it is essential that adequate funding for support and services are made available as a matter of urgency to prevent any further such devastating occurrences.  


Caption: HELPING HANDS: Parents with intellectually disabled children need greater support to help them cope, says a reader. 

Illus: Photo: ahmad elrich 

Section: OPINION 

Type: Letter
The health debate widens dramatically

IT is self-evident that health budgets everywhere in Australia are struggling to keep up with increasing demand.

In this year's State Budget health was allocated an extra $343 million, taking the total to more than $4 billion.

This is an enormous amount of money, even if said quickly. Worse still, costs are bulloooning at around 9 per cent each year.

Hospitals and allied health services throughout the State from the biggest providers to the community volunteer are struggling to keep up with our older and more medically demanding population.

With limited details yet to emerge, the tragic circumstances surrounding the death of a 16-year-old mentally disabled youth on Thursday - allegedly at the hands of his long-suffering mother - appears to suggest a number of patients are falling between the cracks.

Disability groups have been quick to point the finger of blame at a system which they say is chronically underfunded and unable to cope with the mental or physical disability demand in the community.

The victims are the patients, ranging from the alcoholic on the park bench, the depressed carer, the physically disabled newborn or the brain injured car crash survivor.

The State Government's own Social Inclusion Commissioner Monsignor David Cappo calls the situation a "major social disaster".

Prophetically the community organisation Disability Speaks had planned to lobby for increased sector funding this week. It suggested it was "only a matter of time before a distraught parent fatally harms their child."

The group says carers are so overstretched about 80 per cent are suffering from mental health problems.

Even without lagging behind in the funding stakes mental health patients are already burdened with the general lack of empathy in the community for people with these diseases.

All too often those suffering mental disability or illness are dismissed with the generic attitude that they should "get over it" or "suck it up."

In Australia this attitude is part of the national psyche.

Sadly, so much of the South Australian health debate in recent years has been about the State Government option to rebuild the RAH at a new site and the Liberal Party policy to rebuild the existing buildings at the present site.

This ongoing squabble has masked, to some extent, the more substantive issues such as restructuring and demand outstripping supply.

A new hospital is crucial in delivering the state health plan, in terms of improving care, rationalising services and keeping a cap on burgeoning costs.

If this can be achieved, surely then part of any savings could be used to attack the issue of mental and physical disability funding.

Clearly there are too many carers in the community who do not have access to support which could lessen their burden even a fraction.
Care for the family

THE Etizen family is by no means the only family where everything has had to be kept locked for years, where nothing is safe from destruction, where sleep is in shifts so that someone can constantly be on the alert (The Advertiser, 24/7/09).

There are other families where there is no social life, where siblings cannot bring friends home or participate in outside activities, money is short and nobody has had a holiday in years, where the other children have to grow up rapidly and take responsibility for themselves far too soon.

This is the reality of living with a child who has severe behavioural and intellectual difficulties. This is what happens when governments take on a policy of “care in the community” and then use it as an excuse to do little - and, often, nothing at all.

This is what happens when there are not enough respite services and when there is no hope of getting the adult child of older parents into permanent alternative accommodation.

It is the seven-days-a-week, 24-hours-a-day reality for far too many people.

It is what happens when others demand the closure of institutions without first putting in place alternatives and sufficient support services.

The rest of us simply have no idea what it is like to love the child and hate the circumstances. Will this be a wake-up call for the Government and those who demand “care in the community” at whatever cost to others? I doubt it.

The Government will not shift from a policy that costs them less - there are too many other demands on the public purse. There are also many who will say, “But the individual with the disability has the right to live at home and be cared for by their family”.

We also have to care for the family. It is something we spectacularly fail to do, too often with tragic consequences.

K.M. GUNN, Lower Mitcham.

Support system fails

“LOVING and caring mother accused of the murder of her intellectually disabled son” (The Advertiser, yesterday). Once again a person with intellectual disabilities loses their life and a loving family is thrown into turmoil because of the failure of the disability support system to operate effectively in South Australia.

The apparent incapacity of governments of all persuasions to make serious and effective effort in placing support around a person with a disability means we will continue to see such outcomes.

Other desperate parents will just crumble under the weight of expectation that they will continue to care for their sons/daughters, with little in the way of support, until one or the other dies.

For people with intellectual disability to have a reasonable quality of life, it is essential that adequate funding for support and services are made available as a matter of urgency to prevent any further such devastating occurrences.


Bureaucratic murder

I AM sitting, crying at my computer, after a call from a dear friend (another parent of a child with disabilities), telling me about the mother charged with the murder of her disabled son.

While Disability SA offers ongoing services to school-aged families until they reach a self-acknowledged crisis point (as confirmed to me in a group meeting with Disability SA on Friday morning), one child is dead and a family is destroyed.

Every family with a disabled child needs a case worker and regular “check-ups” and families with very demanding children need quality, regular, scheduled, ongoing respite - without having to wait or beg for it.

We need help before we reach crisis point.

My heart aches for this poor mother. It is the bureaucracy that should be charged with murder.

SAM PAIOR (parent of children with disabilities), Panorama.

Vulnerable neglected

THOSE who should be charged in the Etizen case are those who have refused to provide adequate support services for the family and far too many families like them.

Taxpayer funds for support services are not seen as vote winners by governments. The “they have the right to live in the community” policy has been seen as an excuse to put the entire responsibility back on families even for their adult children who would, in other circumstances, have left the family home.

And yes, the rest of us are responsible, too. We should not allow the governments we elect to neglect the most vulnerable and their families.

D.L. THOMAS, Torrens Park.
Jail for mum who sexually abused disabled daughter
July 28, 2009
Western Australia News

A PERTH mother who sexually abused her disabled teenage daughter has been jailed along with a male co-offender after the chance finding of video footage in a police search. The woman, aged 46, was sentenced in the District Court of Western Australia today to nine years imprisonment by Judge Catherine O'Brien who described her offending as a "gross breach of trust".

The woman pleaded guilty to a raft of charges including encouraging her daughter to engage in indecent acts, photographing her naked and sexually penetrating her with a sex toy in 2003 and 2004.

A 30-year-old man who asked the woman to take digital photos of her 13-year-old daughter and made a video of the trio involved in sexual activity was sentenced to eight years and eight months imprisonment.

He pleaded guilty to charges of indecently dealing with a child under 16, encouraging a child under 16 to do indecent acts, indecently recording the girl and sexually penetrating her with an object.

Both offenders, who cannot be named for legal reasons, were also sentenced for possessing child pornography and the mother was convicted of possessing child pornography with the intent to sell or supply it.

Their offending was uncovered when video footage and photographs were found during a search of the man's house in northern WA five years after the abuse, while police were investigating him for another matter. Ms O'Brien said the man was a "driving force" in the abuse and the mother knew the man had a sexual interest in her daughter.

"You put your own needs and desires above the safety of your daughter," Ms O'Brien told the woman in sentencing.

"What you did was a fundamental dereliction of your duty as a parent," she
said.

The pair had met on the internet before becoming involved in a sexual relationship.

The woman will be eligible for parole after seven years while the man will be eligible for parole after six years and eight months.

Ms O'Brien said the offending was in the worst category of its nature by means of its premeditation and the exploitation of a physically and intellectually disabled girl.
Disabled win right of appeal

Cynthia Banham Diplomatic Correspondent
July 30, 2009
The Sydney Morning Herald

AUSTRALIA has cleared the way for people to take complaints about its disability discrimination policies to the United Nations – including prospective migrants with disabled children.

The Rudd Government will announce today that a year after signing the UN Convention on the Rights of People with Disabilities, it intends to accede to the Optional Protocol which establishes a complaints mechanism for breaches of the treaty.

People will only be able to take their complaints to the UN Disabilities Committee if they have exhausted all avenues of redress available in Australia.

The Attorney-General, Robert McClelland, will say in a speech today that “accession to the protocol … not only permits international scrutiny of our laws and practices, but also demonstrates our commitment to re-engage with the international community and to provide leadership in our region."

One potential area where Australia could come under scrutiny is its migration laws, which are exempt from its disability discrimination laws.

Article 18 of the UN Convention recognises the rights of people with disabilities to "liberty of movement, to freedom to choose their residence and to a nationality".