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Characterisation of user-defined health status in older adults with intellectual disabilities

Background Older adults with Intellectual Disabilities (ID) have an excess disease burden that standard health assessments are designed to detect. Older adults with ID have a broader concept of health with dimensions of well being in addition to absence of disease in line with the World Health Organisation’s health definition. We sought to characterize user-defined health status in a sample of older adults with ID.

Methods We administered a user-led health assessment to 57 adults with ID aged 40 years and over. Cluster analysis on user-defined health themes of participation, nutrition and hygiene/self-care identified clear separation of participants into a healthier and a less healthy group.

Results Disease burden (P=0.002) and medication use (P=0.003) were greater in the less healthy group. The healthier group were taller (P=0.005), stronger (P=0.005) and had better vision (P<0.001) than the less healthy group. Constipation (P=0.014), urinary incontinence (P<0.001) and faecal incontinence (P<0.001) were commoner in the less healthy group. There were few significant differences between health groups on the majority of standard physical-examination items.

Conclusion There is considerable overlap between user-defined health and that assessed by standard instruments. In addition, user-defined health encompasses aspects of physical fitness not captured by traditional disease-based health models.

Behavioural flexibility in individuals with Angelman syndrome, Down syndrome, non-specific intellectual disability and Autism spectrum disorder

Background Little is known about behavioural flexibility in children and adults with Angelman syndrome and whether people with this syndrome have more or less problems behaviourally flexible as compared with other people.

Method Behavioural flexibility scores were assessed in 129 individuals with Angelman syndrome using 11 items from the Behavioural Flexibility Rating Scale-Revised (Green et al. 2007). Level of behavioural flexibility scores in individuals with Angelman syndrome (N=129) was compared with that of people with non-specific intellectual disability (ID) (N=90), Down syndrome (N=398) and Autism spectrum disorder (N=233).

Results Comparative analyses show that individuals with Angelman syndrome were more flexible tha those with non-specific ID (P < 0.001) and those with Autism spectrum disorder (P<0.01). There were no differences in behavioural flexibility scores between individuals wit Angelman syndrome and those with Down syndrome (P=0.94).

Conclusion It is concluded that individuals with Angleman syndrome are comparatively flexible in their behaviour.
What Impact does Developmental Co-ordination Disorder have on Daily Routines?

In order to understand how age and motor difficulties impact on daily routines, this qualitative investigation used focus groups and in-depth interviews with Australian and Canadian parents to examine the daily routines of younger (5 to 7 years of age) and older children (8 to 9 years of age) with and without Developmental Coordination Disorder (DCD). Parents were asked to describe the typical school-day routine, one that was not typical and how weekend routines differed. Daily routines were consistent across families and cultures. Older children were expected to participate more independently in the daily routine. The level of structure and assistance provided to children with DCD was greater, and the parents’ expectations of independent performance were lower. Children with DCD required consistent prompting and more structure to complete the morning tasks within the allotted time. Children with DCD were reported to be much happier on weekends and holidays, enjoying the relaxed atmosphere free of the time pressures and tasks of a school-day routine. The main factors that modified participation in daily routines were the child’s age and their motor difficulties.

Motor Coordination and Social-Emotional Behaviour in Preschool-aged Children

School-age children with movement problems such as Developmental Coordination Disorder (DCD) are known to have social and emotional difficulties. However, little research has investigated younger children to determine whether these problems emerge at school age or are present earlier. The aim of the current study was to investigate the relationship between motor coordination, emotional recognition and internalizing behaviours in young preschool children. Forty-one kindergarten children (M=4 years, 4 months), 22 boys and 19 girls, were assessed on the McCarron Assessment of Neuromuscular Development, the Emotional Recognition Scales the Wechsler Preschool and Primary Scale of Intelligence, and the Child Behaviour Checklist. Motor ability was positively related to a child’s emotion comprehension. However, once age, sex, Performance IQ and Verbal IQ were controlled for, it was no longer a significant predictor, which contrasts with previous findings in school-age children. However, the expected correlation between motor ability and anxiety/depression was significant with a moderate effect size. The results indicate that further investigation is required on the relationship between motor ability and social-emotional development in preschool-age children.
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Grandfather's Web browser for autistic boy illuminates the challenges, benefits PCs can bring

June 4, 2008
The Age

John LeSieur is in the software business, so he took particular interest when computers seemed mostly useless to his 6-year-old grandson, Zackary. The boy has autism, and the whirlwind of options presented by PCs so confounded him that he threw the mouse in frustration.

LeSieur tried to find online tools that could guide autistic children around the Web, but he couldn't find anything satisfactory. So he had one built, named it the Zac Browser For Autistic Children in honor of his grandson, and is making it available to anyone for free.

LeSieur's quest is a reminder that while the Web has created important communication and educational opportunities for some people with cognitive impairments, computers can also introduce new headaches for families trying to navigate the contours of disability.

The Zac Browser greatly simplifies the experience of using a computer. It seals off most Web sites from view, to block violent, sexual or otherwise adult-themed material. Instead it presents a hand-picked slate of choices from free, public Web sites, with an emphasis on educational games, music, videos and visually entertaining images, like a virtual aquarium.

Other programs for children already offer that "walled garden" approach to the Web. But LeSieur's browser aims to go further: It essentially takes over the computer and reduces the controls available for children like Zackary, who finds too many choices overwhelming.

For example, the Zac Browser disables extraneous keyboard buttons like "Print Screen" and turns off the right button on the mouse. That eliminates commands
most children don't need anyway, and it reduces the chance an autistic child will lose confidence after making a counterproductive click.

Children using the Zac Browser select activities by clicking on bigger-than-normal icons, like a soccer ball for games and a stack of books for "stories." The Zac Browser also configures the view so no advertisements or other flashing distractions appear.

"We're trying to avoid aggressive or very dark or complicated Web sites, because it's all about self-esteem," LeSieur said from Las Vegas, where he lives. "If they're not under control, they will get easily frustrated."

Autism generally affects a person's ability to communicate, and Zackary doesn't speak much. But his mother, Emmanuelle Villeneuve, reports that the boy can start the Zac Browser himself. He enjoys listening to music through the program and trying puzzles _ things he always liked before but hadn't been able to explore online, she said from her family's home in suburban Montreal.

Perhaps most tellingly, while he still acts out aggressively against the TV, she said, he doesn't try to harm the computer.

LeSieur didn't create the browser by consulting with people who are considered experts in disorders on the autism spectrum. The small software company he runs, People CD Inc., essentially designed the Zac Browser to meet Zackary's needs, and figured that the approach would likely help other autistic children. Early reviews have been positive, though LeSieur plans to tweak the program so parents can suggest new content to add.

Several autism experts were pleased to hear of LeSieur's work, and not surprised that he had not previously found anything suitable for Zackary.

After all, the autism spectrum is so wide that a particular pattern of abilities or impairments experienced by one autistic person might be reversed in another. In other words, creating software that would work for huge swaths of autistic children is a tall order.

Indeed, the Zac Browser might do nothing for another autistic child.
That said, however, LeSieur's approach of limiting distractions and using the software as a confidence-boosting tool "is a very good idea," said Dianne Zager, director of the Center for Teaching and Research in Autism at Pace University. She said many autistic students tend to do best with educational materials that make unnecessary stimuli fade from view.

"Some parts of the Web have so much extraneous material that it can be distracting, and for the nonverbal child, there might not be an ability to negotiate that information," added Stephen Sheinkopf, an autism researcher at Brown University.

This is not to say the Web is necessarily barren for autistic children. James Ball, an autism-education consultant in New Jersey, said many children he works with enjoy Webkinz, where kids care for virtual pets. Others find chat rooms and instant-messaging a lower-anxiety way of socializing than talking to someone in person, he said.

But the Zac Browser might turn out to be the rare tool that can be configured to strike a chord with a wide range of autistic students, said Chris Vacek, chief innovation officer at Heartspring, a special-education center in Wichita, Kan. Vacek is considering using the Zac Browser at Heartspring.

One huge advantage is that the browser is free, while many assistive technologies cost upward of $5,000 (euro3,206) and work only on specialized devices. But Vacek, himself a parent of an autistic child, said the Zac Browser's best credential is that it appears to pass what he calls Heartspring's "acid test": It has a high chance of increasing a child's ability to do things independently.

"Let's hear it for grassroots innovation," Vacek said.
THE disabilities budget will reach $2 billion in 2008-9 for the first time, but advocates say the money falls far short of what is needed to repair a 12-year history of under-investment in accommodation, respite and therapy services.

The extra $130.5 million allocated for services to people with disabilities, their carers, and older people is an an increase of 6.9 per cent over the previous year. As well, an extra $35 million will be spent on building new accommodation units next financial year. This will be supplemented by a one-off boost from the Federal Government of $33.68 million, the state's share of the $100 million disability accommodation package the Prime Minister, Kevin Rudd, announced last month.

The increased funds in the budget were expected as part of the State Government's continued implementation of the Stronger Together program, announced in 2006, which committed an extra $1.3 billion to disability services over five years.

"We're concerned that even with the expected increases in disability funding this year it will not be enough to meet the projected demand," said the director of the NSW Council of Social Service, Alison Peters.

The budget for community services, including child protection and out-of-home care, appears to be in a holding pattern as the Government awaits the recommendations due later this month of the Wood commission of inquiry into the state's child protection services.

The Minister for Community Services, Kevin Greene, said the $1.35 billion community services budget represented an increase of 7 per cent on last year's budget.
But Ms Peters said the real increase was 4.5 per cent over what the Department of Community Services spent last year after blow-outs in spending on out-of-home care.
EDNA MARGARET GLASSBOROW, BEM

SOCIAL WORKER

5-3-1914 — 23-3-2008

EDNA Glassborow, who for more than 60 years worked to improve the welfare of people with intellectual disability, has died in The Alfred hospital, aged 95.

Edna and her husband, Stan, dedicated their lives to the Helping Hand Association, and worked to improve community facilities to support families caring for their own intellectually disabled children.

They also led the development of day-care, school and workshop facilities at Bayley House in Brighton, as well as residential accommodation for intellectually disabled people.

Edna, whose achievements were recognised with the award of a British Empire Medal in 1977, continued to serve Bayley House in various capacities, most recently as a life governor, and contributed to the board until shortly before her death.

The second of three children, she was born behind the family's grocery shop in Gardenvale to her mother Ruby, who closed the shop a couple of hours earlier, and her father, Robert Mathews, a stalwart of the
Methodist Church. Family life revolved around the shop and the church.

Edna looked after the shop after school, and in an era when children were meant to be seen but not heard, she developed skills in logical argument that were to serve her well in later life. She was dux of Elsternwick Elementary School and won a scholarship to business college and held a secretarial job throughout the Depression.

In 1939, Edna married Stanley Glassborow, and they used their savings as a deposit on a new home in South Caulfield. Her first baby, David, died shortly after birth in 1943; the second child, Julene, was born in 1945 with Down syndrome. After recovering from the shock of being told that Julene would always be "subnormal", Edna and Stan rejected the conventional medical advice that would have sent their daughter away to an institution and an early death.

They showed the doctors, and the world at large, what a wonderful person their daughter could become, and had great satisfaction in seeing Julene and her friends at Bayley House grow and flourish. They took pleasure in their achievements at school, in swimming, music and acting, and work. She delighted in Julene's pleasure with her friends, and shared their joy, and the joy of their families.

Edna fought for and welcomed changes in community attitudes that led to increased government funding, but derided others that put parents at arm's length from decisions affecting their children. Her later life was tinged by the sadness of losing Stan from Alzheimer's disease in 1992, and by the death of Julene in 1999.

But her spirit was indomitable. Despite episodes of ill-health in later years, she was determined to continue living in the same home that she had gone to as a young bride in 1939. With the help of close friend Faye Barrow, other friends and relatives, and her church, she succeeded in that goal. In her organised way she also left detailed instructions for her funeral.
Edna achieved a great deal. Had she been born in a later era, she might well have become a corporate lawyer or CEO. She will continue to be an inspiration to many as someone whose determination helped to bring happiness out of adversity for very many people.

*John Mathews is Edna Glassborow's nephew.*
Life enriched by care
7/06/2008
The Canberra Times

To get to her literacy course Joanna Boyce needed to take the ferry. Her mother, Sue Boyce, showed her how to use it on her way to work. She showed her the next day, too, and the next, and every morning for the next week or so.

The training wheels stayed on not because Joanna needed them but because her mother enjoyed the morning ride, and when the Liberal senator for Queensland is back from Canberra - and Joanna is not doing the shredding in the Opposition whip's office - they still ride the Brisbane CityCat.

Joanna, 24, is the youngest of the three Boyce children and the only one still at home. She has Down syndrome.

"There's no way I'd ever want to change her," Boyce says, when asked how her daughter's disability has affected her life. In March she told the Senate of her sadness that 70 to 90 per cent of women who discover their foetuses have Down syndrome will opt for an abortion.

"It is my view that the world is a much poorer place without people with Down syndrome."

For a start, Joanna made her a better teacher. "I feel so sorry for my older two kids. It was very much 'Oh, for heaven's sake. This is how you draw an "A". Go and draw one.' I had no sense of how you break things down into tiny, tiny, tiny little steps."

For Joanna, just holding a pen for a few seconds was an achievement. "It was only through Jo that I learned how to teach," Boyce says.

The pair ride the ferry, play tennis and spend a lot of time driving to Noosa, so that Joanna can see her boyfriend. Boyce, a single mother of three, loves it.
Born into a well-to-do family whose wealth was built on septic tanks, Boyce began work as a cadet reporter for The Courier-Mail before moving to Papua New Guinea with her former husband (a former Fairfax correspondent), and Melbourne for a stint in public relations.

Then came a return to Brisbane, where she joined the family company, Everhard Industries, before retiring as chairwoman last year to fill the Senate seat of Santo Santoro, after he resigned in disgrace.

Since joking that she would use her MPs' pay increase to buy pearls to cast before the poor, she has avoided gaffes, which must be difficult for anyone with a tendency to say things that more cautious and dull politicians would never consider uttering (like proposing job-sharing MPs). She opposes Labor's workplace changes, wants to make Parliament and her party more attractive to women candidates, and publicly opposes her leader, Brendan Nelson, on how to treat those with disabilities and mental illness.

Dr Nelson advocates debating the merits of institutions for the mentally ill; Senator Boyce does not.

"Everywhere there's an institution, there is the potential for corruption, abuse, perversion to flourish. The only thing that stops it is that in schools and hospitals ... the community is in there a lot, and has expectations about what happens."

The problem with doing away with institutions, she says, lay in a failure to adequately support those with disabilities or mental illness, who suddenly found themselves living in the community.

But that failure is no reason to lock them back up somewhere "nice and safe" and think this time will be different, she says.

"It's not different, ever, when a place isn't open to scrutiny."

She also parts company with many parliamentary colleagues on how to attract more women to politics.
Her ideas may not be revolutionary in the corporate world but merely mention part-time or job-sharing in Parliament House and you are off the dial.

She acknowledges the concept of job-sharing parliamentarians is problematic, given the obstacles of joint tickets, electoral laws and, probably, the constitution. But she believes it is an idea worth debating.

To be a good local member you need to be empathetic, she says. To be a strong parliamentary performer, you need to be a good debater and unafraid to push yourself forward.

"To find the same skill sets in the same person is pretty unusual, in my view, so why couldn't you have job-sharing of being 'the member'? Now, you run into problems if one becomes the minister, but let's talk about it. There's got to be a way round it."

Perhaps a more achievable short-term goal is her view that the Liberal Party needs to introduce a 30 per cent quota of women candidates in winnable seats.

She is the only woman among seven Coalition senators from Queensland, which also has only one female Liberal representative among 13 Coalition members.

"The electorate votes for people who they think are like them," she says, and a group of mostly male candidates will have no appeal for a group of women voters.

Like many feminists of her generation, she seems baffled at the lack of rage among some younger women, perhaps because some battles have been won, like that on superannuation.

"When I started work at The Courier-Mail women used to pay the same amount into super as the guys, but get 50 per cent of the payout," she says.

"I also think there's been a swing back to conservatism amongst women, which I find unnerving at times."
She is horrified any woman still worries about ironing her partner's shirt, and befuddled at a lack of outrage over unequal pay for equal work.

She criticises the unapologetic workaholism of the Prime Minister - aka, Kevin 24/7 - and the consequent impact on public servants and their families.

She probably feels it personally, what with worrying about Joanna when she is away.

When she is back they continue Joanna's introduction to opera. Last year, it was Puccini's La Bohème, in which Mimi dies of consumption in a Parisian garret during the final act.

While Mimi was quietly expiring, Joanna was quietly sobbing, attracting the attention of others in the audience who thought it "cute" before realising it was in fact rather sad.
God's love in a time of social turmoil
BY GRAHAM DOWNIE
9/06/2008
The Canberra Times

Supporting men with intellectual disabilities, psychiatric illness, chemical addictions and criminal convictions has been the major focus of Queanbeyan's Michael Cockayne over the 38 years of his Anglican priesthood.

Canon Cockayne's dedication and service have been recognised with the award of a Medal of the Order of Australia (OAM) in today's Queen's Birthday honours.

"It is embarrassing," he said at first. But, on reflection, he said it recognised the work of the entire Celebration Community that he established 35 years ago as a young priest in the rural parish of Koorawatha.

Canon Cockayne became rector of Christ Church Queanbeyan in 1978, where he is a member of the team ministry for the Anglican parish of Greater Queanbeyan.

"I live in a religious community and no one pays me," he said. The community is sustained by a fee for its men's shelter and by donations.

Canon Cockayne admits to having been something of a troublesome priest to three of the four bishops under whom he has served: "I have caused some discomfort, but they loved me. I often say, if it were not for God I would be the most selfish and self-centred person around."

He is passionate about his work but admits to frustration: "You work with people who are mostly ungrateful but you achieve great things. I get very mad at people but in a controlled way always with love."

Born in London in 1944, he arrived in Melbourne in 1950 on a migrant ship. He attended Geelong Grammar and Melbourne University and "knew I wanted to be a priest since the age of 14".

Canon Cockayne said what kept him going was faith that good would triumph in the end.
HARRIET Johnson, a feisty champion of the rights of the disabled who came to prominence in the United States after she challenged Australian bioethicist and philosopher Peter Singer's contention that severely disabled newborns could ethically be euthanised, has died at her home in Charleston, South Carolina. She was 50.

No cause has been determined, her sister Beth said, while pointing out that her sister had been born with a degenerative neuromuscular disease and that "she never wanted to know exactly what the diagnosis was".

The condition did not stop Johnson from earning a law degree, representing the disabled in court, lobbying legislators and writing books and articles that argued, as she did in The New York Times Magazine in February 2003, that "the presence or absence of a disability doesn't predict quality of life".

Using a battery-powered wheelchair in which she loved to "zoom around" the streets of Charleston, Johnson playfully referred to herself as "a bedpan crip" and "a jumble of bones in a floppy bag of skin".

Rolling into an auditorium at the College of Charleston on April 22, 2001, Johnson went to the microphone during a question-and-answer session to confront Singer, the professor for human values at Princeton University, who was giving a lecture titled "Rethinking Life and Death". The title of the lecture mirrored the name of the former Monash University professor's book that won the National Book Council of Australia's prize for the best non-fiction book published in
Australia in 1994.

Singer had drawn protests by insisting that suffering should be relieved without regard to species. That, he said, allows parents and doctors to kill newborns with drastic disabilities such as the absence of higher brain function or an incompletely formed spine, instead of letting "nature take its course".

In Singer's view, infants, like other animals, are neither rational nor self-conscious. "Since their species is not relevant to their moral status," he said, "the principles that govern the wrongness of killing non-human animals who are sentient but not rational or self-conscious must apply here, too."

Johnson had been sent to the lecture by Not Dead Yet, a national disability rights organisation. Describing the event in *The New York Times*, she wrote: "To Singer, it's pretty simple: disability makes a person 'worse off'. Are we 'worse off'? I don't think so." She added: "We take constraints that no one would choose and build rich and satisfying lives within them. We enjoy pleasures other people enjoy, and pleasures peculiarly our own."

An email exchange followed that encounter in Charleston, leading to an invitation to debate Singer at Princeton on March 25, 2002. Their two encounters were the subject of the 8000-word *Times* article, which brought Johnson considerable attention in the disability rights movement and from the general public.

"Her impact came mostly from her writing," said Laura Hershey, a disability rights activist with several organisations, including Not Dead Yet. "Millions of people by now have read that article, and it was reprinted in her book. Dozens of people who read the article told me, 'Wow, I never thought about it that way'."

Johnson's memoir, *Too Late to Die Young*, was published in 2005. Her
novel, *Accidents of Nature*, about a girl with cerebral palsy who had never known another disabled person until she went to camp, was published in 2006.

Johnson was born in Laurinburg, North Carolina, and was one of five children. Her parents, David and Ada, taught foreign languages at colleges.

The fact that her parents could afford hired help was a salient point in another magazine article she wrote in 2003, "The Disability Gulag". Describing institutions where "wheelchair people are lined up, obviously stuck where they're placed" while "a TV blares, watched by no one", she called for a major shift from institutionalising people to publicly financing home care provided by family, friends or neighbours.

"I sometimes dare to dream that the gulag will be gone in a generation or two," she wrote. "But meanwhile, the lost languish in the gulag."

Johnson started her hell-raising at 14, when she tried to get an abusive teacher fired at a school for the disabled. Also in her teens she describes in her memoir how, after watching a Jerry Lewis muscular dystrophy telethon, she turned against "the charity mentality" and "pity-based tactics". Johnson graduated from Charleston Southern University in 1978, then earned a master's degree in public administration from the College of Charleston. She graduated from the University of South Carolina School of Law in 1985 and soon went into private practice.

Humour laced her writing. The "crippled children's school" she attended as a teenager, she wrote in a *Times* opinion article in December 2006, once considered staging a play based on Charles Dickens' *A Christmas Carol*. But who would be Tiny Tim? Johnson quoted from the Dickens book: "Alas for Tiny Tim, he bore a little crutch, and had his limbs supported by an iron frame!"
"Alas!" Johnson exclaimed. "A little crutch! An iron frame! In our world, the crutch-and-brace kids were the athletic elite. They picked up the stuff we hard-core crips dropped."

Johnson is survived by her parents David and Ada, her sister Beth and brothers Eric, McBryde and Ross.

NEW YORK TIMES, THE AGE

HARRIET McBRYDE JOHNSON

ACTIVIST FOR DISABLED

8-7-1957 — 4-6-2008

By DENNIS HEVESI
Virgin disabled policy suit 'in public interest'

June 18, 2008 – The Age

A Sydney judge has ruled that a discrimination suit against Virgin Blue's disability policy is in the public interest, and has made an order helping it to proceed.

Maurice Corcoran, president of the Federation of Disability Organisations, has joined with passenger Tom Ferguson to lodge a public interest suit in the Federal Court of Australia.

The suit follows controversy in 2006 over Virgin's Independent Travel Criteria (ITC), which Mr Corcoran and other disability support groups heavily criticised.

According to a statement of claim filed in the court, the ITC requires anyone who is unable to reach the oxygen mask, put on a life jacket, fasten a seatbelt or understand instructions to travel with a carer.

"Mr Corcoran and Mr Ferguson each claim that they are unable to comply with the ITC, and have commenced proceedings claiming that, in implementing and applying the ITC, Virgin has discriminated against them, directly and indirectly," court documents state.

Justice Annabelle Bennett this week capped costs in any judgment against Mr Ferguson at $15,000 and at $40,000 for Mr Corcoran, allowing them financial leeway to proceed with their case.

Both men had submitted that any prohibitive costs order, were they to lose, could deter them from continuing the case.

Justice Bennett said the issue was one of considerable community importance.

"The ability of disabled persons to fly with Virgin, a major commercial airline in Australia, without the extra cost of a carer raises questions of public interest
beyond the private interests of the applicant," she said.

Virgin also considered the case to be of vital importance to its operations, she said.

"Virgin says that if it is not able to implement the ITC, its officers and employees will be exposed to a risk of prosecution and civil actions," Justice Bennett said.

"Further, (it claims) that its employees' and customers' safety could be compromised."

The men will call evidence in relation to travel provisions for unaccompanied minors, the regulations of other airlines, and confidential information obtained from Virgin about why the policy was adopted.

Their counsel is expected to argue that Qantas is the benchmark for the treatment of passengers with disabilities.

Virgin will call extensive evidence about the history of and use of the ITC, including amendments made in 2003, 2006 and 2007.

It will also demonstrate the vital actions passengers must be capable of undertaking, and outline staff responses to mid-air turbulence or cabin decompression and emergency aircraft evacuation, including ditching over water.

Virgin accepts Mr Ferguson cannot comply with the ITC, but is disputing the legitimacy of Mr Corcoran's claim.

Neither man is seeking personal compensation.

AAP
Handicapped heroes with feet of clay
John Huxley
June 19, 2008
The Sydney Morning herald

FOR someone who learnt the fundamentals of sailing from a Rod Stewart record, putting to sea on Time and Tide was an unnerving albeit uplifting experience. The round-the-world racing yacht was crewed entirely by disabled sailors: the profoundly deaf, the heart-impaired, the cerebrally palsied, the partially blind, the variously limbless and me, the merely useless.

The day started under still, clear, blue skies. But several kilometres off Wellington, New Zealand, the weather changed. The wind came howling off the Cook Strait. The sea cut up increasingly rough.

Suddenly, something went wrong with the big sail at the pointy end, which instead of billowing had become snagged and was flapping wildly, tying itself into knots.

Hiding down the blunt end, all I could do - all I was allowed to do - was watch as the skipper, James Hatfield, a hole-in-the-heart survivor, attracted the attention of his deaf sidekick by hitting him across the head, and yelled at two one-legged men, and one one-armed man fighting a life-and-death battle with several square kilometres of sail. "Fix it. Fix the f---ing thing!"

The remarkable story of "Hatfield's heroes", four of them Australian, was eventually told in a book, On Equal Terms. The author, Marina Cantacuzino, chronicles the heroism of the crew: one amputee broke his remaining leg and had to be lashed to his bunk for several days.

But she does not patronise, honestly pointing out other, more human qualities: their weaknesses, their incompetencies, their occasional bouts of self-pity, their jealousies, falling-outs and moans, most often directed at the admirable skipper, who was criticised as a slave-driver and a sulk, who went days without talking to his crew.
Thoughts turned to Time and Tide this week on learning that one, possibly two, disabled athletes will be competing at the Beijing Olympics - on equal terms. The South African Natalie Du Toit, who lost her left leg after being hit by a car, has qualified for the 10 kilometre open-water swim.

A countryman, double-amputee Oscar Pretorius, who runs with carbon-fibre blades attached, hopes to run the 400 metres. Best wishes to them - and the thousands of other disabled athletes training for September's Paralympic Games, where "equal terms" must be established through detailed classification. Let's hope they get the attention and applause they deserve.

For the record, Time and Tide finished the race last but without further serious mishap. Not so fortunate was the able-bodied Englishman sailor Paul Stephens. Having survived the treacherous seas of the Southern Ocean, he was forced to retire after severing arm muscles in a "shark attack" on dry land, when a glass tank shattered at the Sydney Aquarium. As he so rightly concluded: "You've got to laugh."
Crackdown on parking cheats

Lisa Carty NSW Political Editor
June 22, 2008
Sydney Morning Herald

PARKING officers will be given new powers to confiscate disability parking cards immediately from cheats who abuse the system.

In the crackdown, to be announced by Roads Minister Eric Roozendaal, motorists not entitled to the cards will face tough sanctions, including a "three strikes and you're out" policy.

And doctors will be reminded of their obligation to ensure they recommend only eligible people for the Mobility Parking Scheme.

Mr Roozendaal said the community was fed up with people taking illegal advantage of the scheme.

Cardholders can park in disabled parking zones and leave vehicles in time-restricted spots for double the posted time. In some cases, they can stay all day without being fined.

"The scheme is there to make life easier for people with disabilities, not for parking cheats who don't have a conscience," Mr Roozendaal said. "Parking cheats need to get the message that we will not tolerate the abuse of a legitimate and important scheme for helping people with disabilities."

There are about 281,000 MPS cards in NSW. In the past 18 months, joint RTA, police and council blitzes in the city, North Sydney and Parramatta led to more than 300 fines being issued and 54 cards cancelled.

The crackdown was welcomed by NSW Disability Council chairman Andrew Buchanan, who said action against persistent offenders should be applauded. "It's the comparatively small number of cheats and fraudsters who need to be caught and stopped."

Under the new scheme, the first time a card is revoked for misuse the
cardholder will not be allowed to reapply for another for three months.

"The second time the same offender has their card revoked for misuse, an application will not be allowed for 12 months and if the person commits a third offence, they will not be allowed to reapply," Mr Roozendaal said.

"The RTA will also link MPS card applications to an applicant's medical fitness to drive. This has clear road safety benefits and it will also help deter those people who apply for cards based on false information about a disability. This move allows the RTA to cross-check between the driver's licence information and the MPS to ensure consistency and accuracy of the information."
Govt details $190 million autism package
June 25, 2008
The Age

Parents of autistic preschoolers will receive up to $12,000 over two years to help pay for early intervention programs.

The assistance is part of the federal government's $190 million election commitment to helping children with autism, which was outlined on Wednesday.

The package, which includes a rebate of $6,000 a year to fund early intervention programs, will be available to parents of children aged under six for the two years prior to school.

Up to 3,000 families would be eligible for the rebate this year, parliamentary secretary for disabilities Bill Shorten said.

"Some of the behavioural therapies are very expensive ... but at an early intervention centre, where you've got service providers, we are optimistic that this will go a substantial way," he said.

Mr Shorten said the package was "a re-configuration" of the previous Howard government's election commitment to autism, which was matched by Labor during last year's campaign.

"The Howard government was proposing a lot less into early intervention ... this is principally an early intervention package," Mr Shorten said.

"Early intervention makes a quantum difference in the quality of life for a child with autism."

Under the package, children up to the age of 12 will be eligible for Medicare rebates for diagnosis and 20 visits to allied health professionals.

There is also funding for development courses for 450 teachers to support
students with autism and the appointment of 40 autism advisers Australia wide.

Families in rural and remote areas will also be eligible for an additional $2,000 to help access services.

The government says this part of the package will help 9,000 families.

Autism is a neurological disability with no known cause and it affects an estimated one in every 160 children.

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