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ABSTRACTIONS

Searching for the Hebb effect in Down syndrome: evidence for a dissociation between verbal short-term memory and domain-general learning of serial order

**Background** The Hebb effect is a form of repetition-driven long-term learning that is thought to provide an analogue for the processes involved in new word learning. Other evidence suggests that verbal short-term memory also constrains novel vocabulary acquisition, but if the Hebb effect is independent of short-term memory, then it may be possible to demonstrate its preservation in a sample of individuals with Down syndrome, who typically show a verbal short-term memory deficit alongside surprising relative strengths in vocabulary.

**Methods** In two experiments, individuals both with and without Down syndrome (matched for receptive vocabulary) completed immediate serial recall tasks incorporating a Hebb repetition paradigm in either verbal or visuospatial conditions.

**Results** Both groups demonstrated equivalent benefit from Hebb repetition, despite individuals with Down syndrome showing significantly lower verbal short-term memory spans. The resultant Hebb effect was equivalent across verbal and visuospatial domains.

**Conclusions** These studies suggest that the Hebb effect is essentially preserved within Down syndrome, implying that explicit verbal short-term memory is dissociable from potentially more implicit Hebb learning. The relative strength in receptive vocabulary observed in Down syndrome may therefore be supported by largely intact long-term as opposed to short-term serial order learning. This in turn may have implications for teaching methods and interventions that present new phonological material to individuals with Down syndrome.

Theoretical exploration of the neural bases of behavioural disinhibition, apathy and executive dysfunction in preclinical Alzheimer’s disease in people with Down’s syndrome: potential involvement of multiple frontal-subcortical neuronal circuits
Journal of Intellectual Disability Research, Volume 54 part four April 2010, pp.320-336

**Background** Recent research has suggested a specific impairment in frontal-lobe functioning in the preclinical stages of Alzheimer’s disease (AD) in people with Down’s syndrome (DS), characterised by prominent changes in personality or behaviour. The aim of the current paper is to explore whether particular kinds of change (namely executive dysfunction (EDF), disinhibition and apathy), associated in the literature with disruption of different underlying frontal-subcortical circuits, are a) more or less frequently reported than others and b) related to poor performance on tasks involving different cognitive processes.

**Method** Seventy-eight participants (mean age 47 years, range 36–72) with DS and mild to moderate intellectual disability (based on ICD-10 criteria), without a diagnosis of dementia of Alzheimer’s type (DAT) or other psychiatric disorders, were selected from a larger sample of older adults with DS (n = 122). Dementia diagnosis was based on the CAMDEX informant interview, conducted with each participant’s main carer. Informant-reported changes in personality/behaviour and memory were recorded. Participants were scored based on symptoms falling into three behavioural domains and
completed five executive function (EF) tasks, six memory tasks (two of which also had a strong executive component) and the BPVS (as a measure of general intellectual ability). Multiple regression analyses were conducted to determine the degree to which the behavioural variables of ‘EDF’, ‘disinhibition’ and ‘apathy’, along with informant-reported memory decline and antidepressant medication use, predicted performance on the cognitive tasks (whilst controlling for the effects of age and general intellectual ability).

Results Strikingly, disinhibited behaviour was reported for 95.7% of participants with one or more behavioural change (n = 47) compared to 57.4% with reported apathy and 36.2% with reported EDF. ‘Disinhibition’ score significantly predicted performance on three EF tasks (designed to measure planning, response inhibition and working memory) and an object memory task, (also thought to place high demands on working memory), while ‘apathy’ score significantly predicted performance on two different tasks, those measuring spatial reversal and prospective memory (p < 0.05). Informant reported memory decline was associated only with performance on a delayed recall task while antidepressant medication use was associated with better performance on a working memory task (p < 0.05).

Conclusion Observed dissociation between performance on cognitive tasks associated with reported apathy and disinhibition is in keeping with proposed differences underlying neural circuitry and supports the involvement of multiple frontal-subcortical circuits in the early stages of DAT in DS. However, the prominence of disinhibition in the behavioural profile (which more closely resembles that of disinhibited subtype of DFT than that of AD in the general population) leads us to postulate that the serotonergically mediated orbitofrontal circuit may be disproportionately affected. A speculative theory is developed regarding the biological basis for observed changes and discussion is focused on how this understanding may aid us in the development of treatments directly targeting underlying abnormalities.
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For all the love, living with a disability is hard

March 30, 2010
Sydney Morning Herald

Chris Meney and the Catholic Church may say intellectual disability brings "enormous joy and happiness to families" ("Our society will be worse off if we reject Down syndrome children", March 29). Their religious views may lead them to that position, but the real world is harshly different.

We profoundly love and value our daughters who are affected by Fragile X syndrome, the most common genetic cause of intellectual disability touching thousands of Australians. But even our mildly affected daughters are the first to say, "We would do anything to stop someone having to live with these problems". We are therefore working assiduously with Fragile X Association to expand genetic testing - prenatal, family testing and testing at birth - to prevent more children being born carrying Fragile X, and assist those born disabled.

The association's gatherings would expose the reality the Catholic Church wishes to impose on families. Society does not embrace disability; children face discrimination and social isolation and adults lead difficult lives. The impact is lifelong and constant - doctors, therapies, searching for appropriate schools and jobs, finding friends, coping with difficult behaviour. Inevitably this affects family life, careers and very often marriages.

There is great love also, but that love would prefer others not to have to endure the great difficulty, frustration and sadness that Meney's rosy picture paints over.

Penelope Figgis and Bruce Donald Waverton
Disability activists set for election-year fight

April 3, 2010
The Age

Carers are "mad as hell" about the lack of a national insurance scheme, writes Julie Szego.

For single mother Ursula Nesci, her daughter Giulia's 18th birthday is a milestone laden with anxiety. Giulia, 16, has Rett syndrome, a neurological disorder that becomes apparent between six and 18 months of age.

"She is totally dependent in everything," says Ms Nesci, 51, who has needed shoulder surgery after years of hoisting Giulia into wheelchair, bed and shower.

Skilled care and respite services make Ms Nesci's life just bearable. But they lapse once Giulia - who "lights up the whole world" when she smiles - turns 18. And beyond the immediate challenge of scrambling for alternatives looms the larger problem of what happens once Ms Nesci's capacity to care runs out.

With long waiting lists for permanent accommodation that prioritise older parents, Ms Nesci fears her only option "will be to relinquish her at respite, and then watch her being shunted from one centre to another. And that would destroy me."

Ms Nesci's story is hardly unique given Australia's chronically underfunded and fragmented system of disability support. But the anger of carers and their charges is past the tipping point. They have declared themselves "mad as hell" and are gearing up for an election-year fight.

They are asking people to pledge, via a new website, to vote in state
and federal elections only for parties that promise to introduce a national disability insurance scheme.

The scheme, say proponents, would put the needs of the disabled first. It would end our current crisis-driven approach to providing services. It would also end the lottery, by which people injured in a car accident, for instance, get more entitlements than those who can only blame genes for their fate.

"A fundamental, transformational reform" is how one of the campaign organisers, Sue O'Reilly, describes the goal. She believes the planets are aligning to make disability a politically potent issue. An estimated 1.5 million people have a severe disability, and this is projected to grow to 2.3 million by 2030 as the population ages. About 2 million people, including carers and professionals, are thought likely to vote on this issue alone.

Ms O'Reilly says the campaign has secured pledges "around the 3000-mark, and they're coming in at about two a minute". She believes disability activists could be as powerful as the environmentalists who propelled Bob Hawke to power in the 1980s, the "grey power" lobby in the 1990s and the Women's Electoral Lobby, which put issues such as childcare on the agenda.

The Productivity Commission is investigating the feasibility of an insurance scheme, with its final report due in July 2011. Advocates say the scheme would eventually pay for itself through reduced health and welfare costs. "Governments in total are spending about $20 billion a year on this [disability services] and they're getting appalling outcomes," says Bruce Bonyhady, chairman of community service provider Yooralla. "You've got cases of people waiting years for equipment, like wheelchairs, and when they arrive they don't fit.

"You've got young people in nursing homes because it's cheaper …
wherever you look the system is in deep trouble."

The federal parliamentary secretary for disabilities, Bill Shorten, says disability is underestimated as a political issue by both major parties.

http://australiansmadashell.com.au
When a child with Autism goes to school, both the parents and school personnel want the child to succeed. The best way for that to happen is through honest communication that goes both ways. This article will talk about paraprofessionals that have "one on one" students.

Why Parents Sometimes Don't Communicate
Sometimes a parent doesn't want the staff to know what is going on in her home for fear of looking like a "bad" parent. A good example being a child who doesn't get enough sleep or just plain has a bad morning.

Sometimes parents aren't aware of how things happening at home, affect their child at school. It's not always important to go into specific details about the family, just telling the paraprofessional the parts that effect the child, are sometimes enough.

What is Important to Communicate and Why It's Important
Since paraprofessionals are the people who spend the most time with the child during the school day, they need to know if there is something that might be bothering that child that may hinder or help the learning process. They need to know what bothers a child, what that particular child doesn't like or cannot tolerate to hear, touch or see. Since each child is an individual, what might not bother one child, might make another child very upset.

The opposite is also true of things that might aid learning. One child may love to spin around as a reward, while it might make another sick or upset. These types of things need to be communicated to the people who spend the majority of the school day with the child, which more and more are paraprofessionals.

Also, daily things that come up are important for the paraprofessional to know. The child may not have slept well the night before due to something going on in the house or the next door neighbors dog may have kept him/her up all night. Or possibly, they just couldn't sleep. Who hasn't had the occasional bout of insomnia? Many of these children take medications which interfere with sleep. This might happen quite frequently and a short nap can be built in to the schedule.

According to the Indiana Resource Center for Autism; "A positive relationship and
ongoing communication between staff and family members plays a central role in the educational success of all students."

Is illness going on in the family that the child might be starting to catch? A child that feels sick and doesn't have the words to communicate that will definitely not feel like learning. Since the paraprofessional works closely with the child and gets to know them and their habits quite well, they will be able to look for signs of illness and alert the parents if necessary.

Did the child have a bad morning? Did something upset him before school? Let the paraprofessional know. It might take a little while, but with the knowledge that something happened, the paraprofessional can help with the calming methods that work for each child.

Education.com says that the communication between parents and school staff is imperative for a child's learning, especially a child with Autism.

In turn, a paraprofessional should communicate what has happened during the school day. If a goal has been reached, everyone can celebrate.

**How to Communicate With School Staff**
First and foremost at or before the beginning of the school year, the parents and staff should each have direct telephone numbers. That being said, it's also important to be able to communicate about anything that might come up during the course of a school day, such as illness and behavior issues. Keep the telephone numbers updated as often as changes are necessary.

So, if something has happened that might effect a child's day, the quickest way let the school know would be a telephone call to the teacher or the staff personnel that is responsible for the child's direct learning.

Another way to find out what is going on in the child's school is to set up a daily communication notebook where parents and the paraprofessional and or teacher can write and let each other know what is happening, good or not so good. This would go home with the student each day for the parent to read and come back each day for the school staff to read.

**Communication is Key**
Without communication between parents and schools, the child is at a disadvantage and may not be getting all that is necessary for him to learn.
The federal government has released its plan to change the taxation of trusts to make the system fairer for people with disabilities.

Announced in the 2009-10 budget, the changes will see any unexpended income in the specialised trusts taxed at the beneficiary's personal income tax rate.

Currently, any income not used for care and accommodation is taxed at the top personal tax rate plus Medicare levy.

Parliamentary Secretary for Disabilities Bill Shorten says the changes will make it easier for carers to look after the long-term needs of people with disabilities.

"These trusts have great potential in planning for the future care and accommodation of people with a severe disability," he said in a statement.

"We want to make sure that the legislation reflects the real world people with disability live in and does not stop people with a genuine need from using them."

Special disability trusts were established in 2006 to help carers and families provide for accommodation needs of a person with a severe disability.

Public comment on the government's draft bill is open until the end of April.

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Shorten the white knight for no-fault disability insurance

ADELE HORIN
April 17, 2010

Bill Shorten has been called many names in his trajectory from union leader to parliamentary secretary for disabilities and children's services: Slick Willy, Showbag Bill, "more salesman than substance". Energetic, ambitious, a charmer with a faultless memory for names, there is something about the Labor MP, once touted as a possible future prime minister, that seems too good to be true. Is this guy sincere or just on the make?

Right now many people in the disabilities movement have another descriptor for Shorten, and that is "brilliant". Whatever the motive, Shorten has turned a backwater cause into a politically prominent issue. This week the Productivity Commission began its inquiry into the feasibility of a no-fault disability insurance scheme. It would provide the funds and services for people born with disabilities or who acquire them before the age of 65. As its proponents envisage it, such a scheme would involve an extra 0.8 per cent to be added to the 1.5 per cent Medicare levy, "a big, fat tax", by some reckonings, amounting to about $8 a week extra for someone on average weekly earnings.

You might think such a proposal has zero chance given the mania for cutting taxes. No one expects any action until well after the election, with the commission's report not due until July next year. But the fact the proposal has come this far is due largely to Shorten's drive.

For years, the fragmented disability sector has railed at governments about the appalling state of services for people with disabilities and their families and the lack of respite, supported accommodation, therapy and job opportunities. Each organisation representing its own
constituency - autism, quadriplegia, cerebral palsy - has had its own priorities. I've written many stories in recent years about the plight of parents, on the point of collapse, who care for severely intellectually disabled children.

Funding has increased. But from such a low base and with so much unmet need, the extra has provided little more than a temporary solution.

People with disabilities and their carers are mendicants in what some claim is one of the worst disability systems in the rich world. As more babies with disabilities survive, and more people with disabilities live longer, the problems are going to get worse. The old solutions don't work because mothers who once were full-time carers need to earn a living, and disabled offspring are outliving their parents.

The irony is we have social insurance schemes that work quite well - but only for some and in some states. If you have an accident at work or in a car in NSW, no-fault insurance schemes provide the funds you should need. But if you are in South Australia, Western Australia or Queensland, and are at fault in a car accident, and are disabled, you are on your own.

Around the nation a baby born with cerebral palsy or a teenager who suffers brain injury in a surfing accident is not protected by an insurance scheme and is at the mercy of a crisis-driven bureaucracy for help with equipment, transport, therapy, personal support and housing. The huge difference in treatment of people with similar levels of disability is profoundly unfair.

Perhaps Shorten wondered if he had been stranded in a political no man's land when he got the disabilities gig. But the consummate union campaigner quickly saw he and the cause would get nowhere without effective grassroots agitation. He has toured the country chiding and
encouraging disability organisations to get their act together and help him in the task of persuading the government. His theories about the political importance of the issue, he told a Brisbane gathering in March, were perhaps "unconvincing to my colleagues". He advised the audience the sector needed to be "to be loud and proud, to be organised and to be political, to be consistent and persistent".

Shorten gave the sector official imprimatur when he appointed the Disability Investment Group last year to develop the insurance scheme. Two figures were key in devising it: Bruce Bonyhady, the chairman of Philanthropy Australia, and John Walsh, a brilliant actuary whose quadriplegia led him to an interest in insurance schemes, and who devised the NSW Lifetime Care and Support Scheme for people injured in vehicle accidents. In their draft plan they recommended the government commission a comprehensive feasibility study. That is happening now at the Productivity Commission, with Walsh as associate commissioner.

At the same time the new Australians Mad as Hell website, run by mothers of disabled children, Sue O'Neill and Fiona Porter, has rallied thousands to pledge to vote in elections only for parties that support a national insurance scheme.

It is a once in a generation chance to institute change that cannot easily be wound back. But a scheme could come with a hefty price tag - an extra $4.5 billion a year, according to a PricewaterhouseCoopers estimate, half of which would be set aside to meet future needs. What the commission decides, whether its report becomes "toilet paper", and whether government (and opposition) fudge the chance to make history, has more than Shorten's reputation at stake. Tens of thousands of hearts will be broken if hopes raised so high are dashed.

Source: The Sydney Morning Herald
Ease the pain of air travel for disabled

NICOLAS PATRICK
April 29, 2010
The Age

It is clear that the problems of access for people with disabilities are endemic and have been widely known for some time. As a community we should expect more. Three recent examples highlight the need to follow the US model and lift restrictions on air travel for people with disabilities.

Today a claim against Jetstar by Sheila King is listed for mediation in the Federal Court. King claims she was refused access to a flight on the basis that the flight she booked was already carrying two passengers who required wheelchair assistance. The Jetstar policy restricts the choices and options available to people who rely on mobility devices, meaning they cannot access Jetstar flights on an equal basis with others in the community. King’s experience is not an isolated case.

In November last year, media reported that paralympian Kurt Fearnley crawled through Brisbane airport to board a Jetstar flight. The situation arose because of boarding procedures that require passengers to transfer into an airport wheelchair at the time of check-in. The so-called ‘‘airport wheelchairs’’ do not allow the occupant to move independently, meaning they cannot use airport facilities including toilets. Fearnley said it was the equivalent of having your legs tied together. The use of these chairs by the airline, when other options are available, is demonstrative of a lack of respect for human dignity.

And in December last year, Kathryn Beaton was refused access to a Jetstar flight when two Jetstar employees advised her that the airline
did not carry guide dogs. The incident probably reflected a lack of training, since the airline apparently does allow up to two guide dogs per flight. It is also evidence of a lack of awareness, respect and understanding by employees who deal directly with customers.

In 2002, Australia adopted Disability Standards for Accessible Public Transport, which establish minimum accessibility requirements to be met by providers and operators of public transport companies.

Part 34 of the standards require the Minister for Transport and Regional Services, in conjunction with federal Attorney-General, to review the standards every five years. The draft report after the first five years noted in a sad indictment that it was “a commonly held view that accessibility for people with disability had gone backwards over the previous five years”.

It also noted that people using wheelchairs were frequently refused air travel at the time of check in. Other commonly reported problems included lack of staff training and awareness, and boarding procedures that require passengers to transfer into airport wheelchairs, which cannot be operated by the passenger at the time of check-in.

Following the Fearnley incident, he was quoted in the press as saying: “If this happened in America, the airline wouldn’t be functioning tomorrow.”

The United States’ regulations put Australia to shame. The US regulators come much closer to achieving equal access, because they do not allow airlines to limit the number of passengers who use a mobility device or an assistance animal.

The US regulations require airlines to allow passengers to bring their own wheelchairs into the cabin, demonstrating an approach that respects the needs of the individual passenger. It’s interesting to note that Jetstar is required to comply with the US regulations when it flies
services out of Honolulu. If Jetstar had universally adopted the approach that is required of flights leaving Honolulu, all of these incidents may have been avoided.

Australia has the capacity to be a leader in this area. We have the skills and the resources to end discrimination and to create an inclusive community where all people have equal opportunity to participate in society and realise their full potential.

The Australian government should introduce comprehensive measures to ensure people with disabilities can access transport on an equal basis with others in the community. This would have myriad benefits including reducing social isolation, increasing the employment options available to people with disability, aligning Australian law with the Convention on the Rights of Persons with Disabilities and providing business with the guidance it requires to ensure community expectations are met.

Nicolas Patrick is a human rights lawyer and pro bono partner at DLA Phillips Fox in Sydney. He is representing Sheila King on a pro bono basis in her Federal Court claim against Jetstar and is the lead author of the shadow report on Australia’s compliance with the Disability Convention.