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FEBRUARY 2011
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ABSTRACTIONS

Life and Death of a Child With Down Syndrome and A Congenital Heart Condition: Experiences of Six Couples
Intellectual and Developmental Disabilities, Volume 48 Number 6 December 2010 pp.403-416

Individuals with Down syndrome are at increased risk of congenital heart conditions (CHCs), and mortality is higher in people with Down syndrome and a CHC than those without (J.C. Vis et al., 2009). As a consequence, parents of children with Down syndrome and a CHC are more likely to outlive their child. In this research, semistructured interviews were used to explore the experiences of 6 couples whose child with Down syndrome and a CHC had died. The interviews were analyzed qualitatively using interpretative phenomenological analysis (IPA), and 4 themes emerged: dilemmas associated with the dual diagnosis; treatment decisions during the life and the death of their child (“We had to make a decision”); ways couples coped when bereaved (“We weren’t really going through it together”); and ripples from the child’s life. There was a high degree of similarity of experience within couples. Differences between couples existed in their experiences of coping and supporting each other. Practical implications include the importance of considering the specific needs of couples, individuals, and fathers within partnerships.

Person-Centered Planning: Analysis of Research and Effectiveness
Intellectual and Developmental Disabilities, Volume 48 Number 6 December 2010 pp. 432-453

Person-centered planning is a well known and widely used approach to individual program planning in the field of intellectual and developmental disabilities. Its purpose is to develop collaborative supports focused on community presence, community participation, positive relationships, respect, and competence. Because there is little research on its effectiveness, our purpose there was to (a) review the current status of effectiveness research; (b) describe its effectiveness in terms of outcomes or results; and (c) discuss the effectiveness of person-centered planning in relation to evidence-based practices. Analyzed studies suggest that, overall, this planning has a positive, but moderate, impact on personal outcomes for this population. The body of evidence provided in this review is weal with regard to criteria for evidence-based research.

A description of adaptive and maladaptive behaviour in children and adolescents with Cri-du-chat syndrome

Background Psychological tests can be useful to record adaptive and maladaptive behaviours of children with intellectual disability. The objective of this study was to describe the adaptive and maladaptive behaviour of children and adolescents with Cri-du-chat syndrome.
Methods The sample consisted of 10 children and adolescents with Cri-du-chat syndrome (mean chronological age = 11.3 years, mean mental age = 18 months). The developmental quotient was
calculated through the Psychoeducational Profile – Revised. An observational protocol was used to record adaptive and maladaptive behaviours.

**Results** The number of maladaptive behaviours observed was different among participants. However, all of them had high rates of adaptive behaviours, such as rule-following.

**Conclusions** These results, though preliminary, justify that we continue to think about the need for psychoeducational interventions aimed at stimulating the repertoire of adaptive behaviours, in people with Cri-du-chat syndrome.

**The relationship between specific cognitive impairment and behaviour in Prader–Willi syndrome**

**Background** Individuals with Prader–Willi syndrome (PWS) have been shown to demonstrate a particular cognitive deficit in attention switching and high levels of preference for routine and temper outbursts. This study assesses whether a specific pathway between a cognitive deficit and behaviour via environmental interaction can exist in individuals with PWS.

**Methods** Four individuals with PWS participated in a series of three single-case experiments including laboratory-based and natural environment designs. Cognitive (computer-based) challenges placed varying demands on attention switching or controlled for the cognitive demands of the tasks while placing no demands on switching. Unexpected changes to routines or expectations were presented in controlled games, or imposed on participants' natural environments and compared with control conditions during which no unexpected changes occurred. Behaviour was observed and heart rate was measured.

**Results** Participants showed significantly increased temper outburst related behaviours during cognitive challenges that placed demands on attention switching, relative to the control cognitive challenges. Participants showed significantly increased temper outburst related behaviours when unexpected changes occurred in an experimental or the natural environment compared with when no changes occurred.

**Conclusions** Difficult behaviours that could be triggered reliably in an individual by a specific cognitive demand could also be triggered via manipulation of the environment. Results suggest that a directional relationship between a specific cognitive deficit and behaviour, via environmental interaction, can exist in individuals with PWS.
Life and Death of a Child With Down Syndrome and a Congenital Heart Condition: Experiences of Six Couples
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Demographic and Clinical Characteristics of People With Intellectual Disabilities With and Without Substance Abuse Disorders in a Medicaid Population
Elspeth Maclean Slayter

Person-Centered Planning: Analysis of Research and Effectiveness
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Evaluating a GPS-Based Transportation Device to Support Independent Bus Travel by People with Intellectual Disability
Daniel K. Davies, Steven E. Stock, Shane Holloway, and Michael L. Wehmeyer

Smart Houses and Smart Technology: Overview and Implications for Independent Living and Supported Living Services
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Simon McKeon the Australian of the Year
BREANNA TUCKER
25 Jan, 2011
The Canberra Times

Macquarie group executive Simon McKeon has been announced as the 2011 Australian of the Year.

Mr McKeon is an executive chairman of the Macquarie Group's Melbourne office and specialises in mergers and acquisitions.

At a ceremony on the lawns of Parliament House this evening, the Victorian of the Year was recognised for his extensive commitment to charity after holding executive positions in a range of organisations.

This included being director of World Vision for 12 years, a director of the Global Poverty Project, counselling heroin addicts in St Kilda, encouraging business in the developing world and working with remote indigenous communities.

He is also chairman of CSIRO, works for Multiple Sclerosis, from which he suffers, and held the world speed sailing record until last year.

Queensland solo sailor Jessica Watson was named Young Australian of the Year 2011. NSW disability advocate Professor Ron McCallum AO was announced as Senior Australian of the Year 2011 and NSW suicide prevention advocate Donald Ritchie OAM is Australia's Local Hero 2011.
Sacrifices for family a great investment, says award winner
29 Jan, 2011
Sydney Morning Herald

As he took the stage amid a flicker of camera flashes on a hot Canberra evening, the new Australian of the Year, Simon McKeon, spotted his sister's broad smile in the crowd.

He gave her a little wave. He told the Prime Minister who he was waving to. Then Julia Gillard gave her a little wave too.

"She's had an amazing couple of days," McKeon said this week. "She's been very supportive."

McKeon's involvement in his sister Diane's life and the lives of her two children is credited by McKeon and his friends as being central to making him the man he is. Di, 66, was born with an intellectual disability.

"He is scripted by seeing that you can really make a difference, even though it is [by] shouldering heavy responsibilities," says his friend and fellow social campaigner, Tim Costello.

The multiple talents of McKeon, 55, have been well covered this week. There is his role as a game-changing corporate philanthropist. As a sailor he has broken world records by pushing yachts to 100km/h. As a talented Macquarie Group investment banker, he brought harmony to the cut and thrust of corporate takeovers. Throw in the chairmanship of Australia's science agency, the CSIRO, and a debilitating brush with multiple sclerosis in 2002, and you have an extraordinary individual.

What has been less well covered is how McKeon and his family, who live in the Melbourne suburb of Brighton, made significant sacrifices to embrace and care for his sister and her children. McKeon plays down his role. "Family is a non-negotiable," he says. But some of his closest friends cite the enduring relationship as both a forge and a touchstone for the man he has become.

The official video introduction of McKeon's award on Tuesday referred briefly to his role in his sister's life.

McKeon remembers the moment at the ceremony: "She raised her fist up with the biggest grin on her face I have seen in years, as if to say: 'That's me'."

Beyond the video introduction, the story is complicated and, at times, tragic. McKeon's role has exposed him to the great challenges facing the less able in society, including the roles played by the judiciary and the bureaucracy. "I guess the story I'm trying to tell is, for whatever reason, I have had an exposure to another side of life. I guess it's another reason why I end up where I am," he says.
McKeon is frank and engaging as he grapples with questions about the emotional impact of caring for Di on him, his wife Amanda Jane McKeon, and his family of four sons: Brook, 25, Richard, 23, Oliver, 20 and Sam, 18. "The cost has been considerable," he says. "The reward, the benefit, the fulfilment has been a multiple of that considerable investment."

McKeon returned to Melbourne in 1984 after four years in Sydney, despite a promising career as a young lawyer, to take over his sister's care from his flagging parents. Di moved so she was close to the McKeon household. The task eventually involved a central role in caring for Di's two children from her first marriage, Jill and Tony, expanding McKeon's young family from four to six.

"We're not Catholics but we felt like Catholics at the time," McKeon jokes.

Tragically, Tony died in a train accident as a young man in 2001.

McKeon says experiences with Di had led him to question his ultimately strong religious faith. He remembers returning to his home after one incident at 4am and walking to the beach in a raging gale, addressing the skies: "If there's a God up there, please explain to me why you have presented to me the crap you have".

Michael Traill, the chief executive of Social Ventures Australia, hails McKeon as a trailblazer in melding corporate skills with traditional not-for-profits, a growing field referred to as "social business".

"He's a guy who has done a serious job, an authentic job, of connecting his head and his heart," Traill says.

McKeon traces his work in social organisations, which led to him cutting back his work with Macquarie to a part-time role in 1994, to his upbringing in the outer Melbourne suburb of Dandenong. "It would actually be my childhood; I was very privileged to grow up in one of Melbourne's poorer suburbs â I took for granted that where there was a need you would see a services organisation," he says.

"I just never wanted those feelings that I cherished as a young boy to disappear."

McKeon's breadth is captured in an interview with the Herald by his ability to talk enthusiastically about the ground-breaking work of the Nobel peace prize winner Muhammad Yunus. (Yunus was brought to Sydney last year by a charity McKeon chairs, Business for Millennium Development.) Seconds later, McKeon can address technical questions about his 10 years chairing the Takeovers Panel.

"The interesting thing about Simon is his tremendous capacity to work on multiple things with great intensity," says an executive director at Macquarie, Robin Bishop, who has worked alongside McKeon for 15 years.

McKeon's humanist philosophy is captured in the simple gesture of inviting the Herald's photographer to stay for dinner late on Thursday, despite a media whirlwind that has engulfed the family in the past few days.
His stated goals for his time as Australian of the Year are deceptively modest. "I would like to do all I can to widen [people's] choice of time and money to include giving back through the non-profit sector. There's a role for all of us," he says.

Bishop has no doubt he will succeed in pushing his message. "Knowing Simon's tremendous energy, capability and enthusiasm, I'm sure as Australian of the Year he will greatly enhance the level of participation by business in the not-for-profit and community sector," he says.

Costello, who has known McKeon since he met him through a charity called Urban Seed more than 14 years ago, is ambitious on his behalf.

He points to the galvanising effect on corporate America of the Microsoft entrepreneur Bill Gates's massive campaign of philanthropy. "I think Simon has the potential in this country to do a wake-up call similar to that of Bill Gates in America," he says.
Media Release

Wednesday 9 February 2011

"To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent human dignity."

UN Convention on the Rights of Persons with Disabilities

Employment - the key to life!

National Council on Intellectual Disability today hosts a forum on employment for people with intellectual disability. The keynote address is being presented by Mr Christy Lynch (CEO of Kare - Ireland).

Christy Lynch has for 20 years supported people with intellectual disability to get real jobs at award wages.

"I am surprised", said Mr Lynch, "at the slow pace of reform in Australia. Unlike advances in other countries where people with intellectual disability are moving out of segregated settings. Segregated settings exist because governments fund them. If the government does not fund services that find people with intellectual disability jobs in the community paying full award wages then people will not get these jobs."

Christy began in his current job by closing down the segregated sheltered workshop and getting people jobs in the community paying award wages. His knowledge and experience will be invaluable as Australia debates welfare reform and the equal participation of people with intellectual disability in the economic life of Australia.

As the Prime Minister, Julia Gillard has said, "we want (people with disability) to gain the benefits that come from having a job: increased income; social engagement and friendship; self-esteem and wellbeing".

Christy Lynch and Australia's leading providers demonstrate that by using evidence based practice people with significant disabilities are good employees earning award wages. For them it is not a matter of words and theories but action.

The 'Employment - the key to life' forum will hear about the high cost of shutting people with intellectual disability out of employment, to them and the taxpayer.

"This is a missed opportunity," said Mr Lynch, "a missed opportunity for people with intellectual disability to escape poverty and become involved in their community, a missed opportunity for governments to implement their human rights responsibilities and to reduce DSP expenditure and a missed opportunity for service providers to be the best, to challenge their staff to have high expectations and to achieve."

Contact:

Mark Pattison, Executive Director, 0407 406 647
Disability housing model to ease the pressure on families
BY BIANCA HALL
15 Feb, 2011
The Canberra Times

Sally Richards's family has been stalked by tragedy, but she remains resolute.

The Yarralumla mother of four sons is the sole carer for her 25-year-old son Jackson, who has severe intellectual disabilities and a host of physical complaints.

She has cared for her son alone since her husband Malcolm West died at his own hand while in treatment at the Hyson Green psychiatric facility in 2009.

Last year an inquest into Mr West's death was told he had been under pressure at work and was having difficulty coping with caring for Jackson, who needs 24-hour care.

Since 2005 Ms Richards and two other mothers of young people with disabilities Cheryl Patrick, mother of Ben, and Karen Connaughton, mother of Daniel have campaigned for a new housing model that would give their sons a home, and ease the pressures on family carers.

Yesterday their dream came one step closer to being realised.

Disability, Housing and Community Services Minister Joy Burch launched a new social housing project, funded with about $7 million from Housing ACT's home loans fund.

Ms Burch said a new "intentional community" development, to be located on a vacant block of land in Phillip, would combine about 20 public housing dwellings with a handful of homes for young people with disabilities.

"It sets these young adult men up for life and it lets them live in a supportive neighbourhood," Ms Burch said.

"The new community will provide an innovative accommodation option for people with a disability, who will live independently whilst receiving a mix of formal and informal support, as well as ongoing support from their families."

The public housing tenants will be vetted for those who are happy to live in the housing model, a first for the ACT.

Jackson, Ben and Patrick will live in the development, which still needs planning approval.

It may still be some time off, but Ms Richards said the proposal had been a long time coming.
"It's incredibly hard," she said, before catching herself. "It's fine. You just can't do it by yourself forever."
ALREADY under pressure over the carbon tax and floods levy, Prime Minister Julia Gillard will today face calls for a third new tax, a Medicare-style national disability insurance levy costed at $5 billion.

The levy, to be announced in the interim report of a year-long Productivity Commission investigation, would be set at 0.8 per cent of income on top of the 1.5 per cent Medicare levy, bringing the total impost to 2.3 per cent.

An alternative option would collect money in the same way as the superannuation levy, at an average cost of about $400 a year per worker.

"Right now if you lose the use of your limbs falling off a ladder you are without support," said former New South Wales government minister John Della Bosca.

"But if you lost use of limbs in a car you would be fully covered. It'd make sense to get up, get into a car and crash it."

Mr Della Bosca introduced Victorian-style compulsory no-fault car accident cover to NSW and believes both states have left the job half finished.

As campaign director for the lobby group Every Australian Counts, he is confident the commission will today recommend compulsory lifetime cover for all disabilities however inflicted, including those acquired at birth.

He is less certain about how the commission will suggest it be funded.

"I think it will set out options, the primary one being a Medicare-style levy. I would like to say to my political colleagues this isn't the sort of levy you should build a scare campaign around."
“Doing nothing to provide disability cover is not an option. It can happen to anyone at any time, and it can happen to anyone's kid any time. Right now on a completely arbitrary basis some are denied support.

"The sector doesn't like me saying this, but it is true. Without support, carers get burnt out. If carers can't get support they eventually break down and can't continue caring for their children."

Australian National University professor Warwick McKibbin, a passionate critic of the government's flood levy, supports the idea of a disability levy, saying that while one is bad in principle, the other makes economic sense.

"One of the key things a government can do well is bundle the risk of a whole bunch of people and make it cheaper for everybody," he says.

Victorian Premier Ted Baillieu is backing a national insurance scheme as are NSW leaders Kristina Keneally and Barry O'Farrell.

The total cost of caring for the 850,000 severely disabled Australians is estimated at about $10 billion per year; about half is funded through motor vehicle third party insurance. Mr Della Bosca says the cost of the other half should come down over time as people were case managed and returned to work.
Relatives fight to keep centre for disabled open

Michelle Griffin
February 28, 2011

Sandra and Noel Bates with their severely intellectually disabled son Craig, 45, at Colanda. Plans to close the institution are "ideologically driven", says Mr Bates. Photo: Robin Sharrock

THE future of one of Victoria's last big institutions for the disabled is on the line today as relatives of the residents of Colac's Colanda centre meet parliamentary secretary for community services Andrea Coote to plea to keep it open.

Meanwhile, disability activists are calling on Minister for Community Affairs Mary Wooldridge to close Colanda, home to about 115 intellectually disabled adults, along with Bendigo's smaller Sandhurst Centre, as the last dinosaurs of an age when the disabled were locked up and out of sight.

"The closure of institutions is ideologically driven," says Noel Bates, 77, president of the Colanda Parents and Friends Association. "We're not pro institutions, we're pro better services for the disabled, including
upgrading the facilities here. Colanda is 35 hectares of beautifully laid out parkland, a beautiful environment. It has newer facilities [than Kew Cottages had], better staff and processes."

Mr Bates' son Craig, 45, suffers from Angelman's Syndrome and has, his father says, "the intellect of an 18-month-old". He suffers from seizures, cannot speak, or care for himself. He is unsteady on his feet and does not know his own strength when he reaches out to hug his mother, Sandra.

Although their doctors told the Bateses in 1966 to send their baby away and forget about him, they kept Craig at home until he was eight. After two years at Kew Cottages, he was admitted to Colanda the year it opened, 1976, and has lived there since.

"It was much, much better compared with what was available at Kew," says Mr Bates. "It was an upmarket facility - it still is, for that matter."

But despite Colanda's bucolic gardens, solid brick units and honourable reputation, many in the disability sector say it should be shut as soon as possible, and the residents integrated into the community, like the residents of Kew Cottages.

A 2008 report on Colanda for the Department of Human Services noted the relatives' satisfaction with the quality of care, but concluded that the routines of a large-scale institution restricted the residents' "individual choices … and their quality of life".

"They should close it yesterday," says Kevin Stone, executive office of the Victorian Advocacy League for Individuals with Disability.

"As far as I am concerned, it belongs in a previous age. The tragedy is that these are the people time forgot."

Community Affairs Minister Mary Wooldridge told The Age she wants to consider several options for Colanda and did not rule out the establishment of a cluster of smaller units on the grounds, similar to the "campus" in Plenty that replaced the Janefield institution.
"Colanda and Sandhurst do need to close," she said, "but we have not put a time frame on that."

Ms Wooldridge said that the 1239 Victorians wait-listed for supported accommodation "who are now staying with families or in rooming houses" were a more urgent priority for rehousing "than those at Colanda and Sandhurst, who have accommodation".