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ABSTRACTIONS

The abstracts below are taken from journals, the contents page of which are included in this month's Information Service. These abstracts are provided as a response from Information Service members who have asked us to provide more information about the articles contained in our contents' page.

Adults with mild intellectual disabilities: can their reading comprehension ability be improved?

Background Adults with a mild intellectual disability (ID) often show poor decoding and reading comprehension skills. The goal of this study was to investigate the effects of teaching text comprehension strategies to these adults. Specific research goals were to determine (1) the effects of two instruction conditions, i.e. strategy instruction to individuals and strategy instruction in small groups in a reciprocal teaching context; (2) intervention programme effects on specific strategy tests (so-called direct effects), and possible differences between strategies; (3) (long-term) transfer effects of the programme on general reading comprehension ability; and (4) the regression of general text comprehension by the variables of technical reading, IQ, reading comprehension of sentences (RCS), and pretest and posttest scores on the strategies taught.

Methods In total, 38 adults (age range 20–72 years; mean age of 36 years) with ID participated in the study. IQs ranged from 45 to 69 with a mean IQ of 58. The intervention programme involved 15 weekly lessons of 1 h each, taught during 3 months. Blocks of lessons included each of Brown and Palincsar’s strategies of summarizing, questioning, clarifying and predicting, as participants read and studied narrative and expository texts.

Results Results indicated no significant difference between group and individual instruction conditions. Second, direct programme effects – as determined by posttest–pretest contrasts for strategy tests – were substantial, except for the questioning strategy. Third, even more substantial was the transfer effect to general text comprehension. Moreover, the results on this test were well maintained at a follow-up test. Finally, the variance of general reading comprehension ability was best explained by the test of RCS, and only moderately by the strategies trained.

Conclusion The presently used intervention programme provides a good starting point for adults with ID to become better readers.

Self-determination, social abilities and the quality of life of people with intellectual disability

Background The international literature has documented that self-determination is impacted by environmental factors, including living or work settings; and by intraindividual factors, including intelligence level, age, gender, social skills and adaptive behaviour. In addition, self-determination has been correlated with improved quality of life (QoL). This study sought to contribute to the growing literature base in this area by examining the relationship among and between personal characteristics, self-determination, social abilities and the environmental living situations of people with intellectual disabilities (ID).

Methods The study involved 141 people with ID residing in Italy. Healthcare professionals and social workers who had known participants for at least 1 year completed measures of self-determination, QoL and social skills. Analysis of variance was conducted to verify whether different levels of intellectual impairment were associated with different degrees of the dependent variables. The Pearson product–moment correlation was used to examine any relationships among dependent variables and IQ.
scores. Finally, discriminant function analysis was used to examine the degree to which IQ score, age, self-determination and social abilities predicted membership in groups that were formed based on living arrangement, and on QoL status (high vs. low).

**Results** The anova determined, as expected, that participants with more severe ID showed the lowest levels of self-determination, QoL and social abilities. Discriminant function analysis showed that (a) individuals attending day centres were distinguished from those living in institutions in that they were younger and showed greater autonomy of choice and self-determination in their daily activities; (b) basic social skills and IQ score predicted membership in the high or low QoL groups; and (c) the IQ score predicted membership in the high or low self-determination groups. A manova conducted to examine gender- and age-level differences on self-determination found gender differences; women had higher self-determination scores than men.

**Conclusions** These findings contribute to an emerging knowledge base pertaining to the role of intraindividual and environmental factors in self-determination and QoL. In general, the study replicated findings pertaining to the relative contribution of intelligence to self-determination and QoL, added information about the potential contribution of social abilities, and pointed to the potentially important role of opportunities to make choices as a particularly important aspect of becoming more self-determined, at least in the context of residential settings.

**Quality-enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature**

**Background** This study provides an overview of empirical research on the effectiveness of quality-enhancing interventions for people with profound intellectual and multiple disabilities (PIMD).

**Method** Through computerized searches of the PsycINFO and ERIC databases, and using several search criteria specifically relating to the target group and to the subject of this review, 16 studies were identified.

**Results** The interventions described are targeted at the physical and material well-being, emotional well-being, social interactions, choices, and personal development of individuals with PIMD, but do not address community participation and rights. The majority of the studies report positive effects of the interventions on staff and/or client behaviour. However these effects should be interpreted with caution because of methodological and other considerations.

**Conclusions** Current research gives only limited insight into the effectiveness of quality-enhancing interventions for people with PIMD. To foster evidence-based practice, further studies of larger groups and with more robust designs are warranted. The potential differential effects associated with client characteristics and the context of the implementation should also be considered.

**Social relationships and friendships of children with developmental disabilities: Implications for inclusive settings. A systematic review**

**Background** The engagement of children with developmental disabilities (DD) in social relationships with typically developing peers has become increasingly important as inclusive practices have become more the norm than the exception. This paper provides an overview of the research on social relationships between these two groups.

**Methods** Studies were included if they provided a naturalistic examination of the relationships between children with DD (from the age of 3 years to school exit) and peers they have met in school or in age-appropriate educational settings.

**Results** A total of 36 studies are reviewed, providing a framework for analysis of the relevant research, with a particular focus on implications for inclusive settings. Three specific areas are address: (a) features of social relationships; (b) types of social relationships and roles assumed by the individuals involved; and (c) the existence and nature of friendship within these relationships.

**Conclusions** Research on relationships between children with DD and their peers in inclusive settings is patchy, limited in context, and non-linear in its development. Directions for future research are discussed, together with a range of methodological issues that should be considered.
Parent-Professional Partnerships: A valuable context for addressing challenging behaviours
International Journal of Disability, Development and Education Volume 54 Number 3 September 2007 pp.273-286

Partnerships between professionals and parents of children with disabilities can be valuable ingredients in efforts to design and implement strategies of intervention and support. In this article, we provide a rationale in support of parent-professional partnerships and describe research and programmes that exemplify such partnership practices. We also describe approaches for facilitating the development of partnerships and a framework in which partnerships are placed at the optimal end of a continuum of parent involvement and parent support.

Moving towards Midlife Care as Negotiated Family Business: Accounts of people with intellectual disabilities and their families “Just getting along with their lives together”
International Journal of Disability, Development and Education Volume 54 Number 3 September 2007 pp.287-304

This study explores meanings of family care held by seven families that include a middle-aged adult with intellectual disability. In-depth interviews were conducted with members of each family—the person with intellectual disability, parents, siblings, and sibling spouses. Participants described care as simply getting on with their lives, as “Family Business”, characterized by the conduct of well-understood tasks and routines. As such, all, including the person with intellectual disability, performed roles critical to the well-being of each other and the family as a whole. Family Business was underpinned by negotiated, albeit often implicit, rules that reflected family values and were amenable to changes in circumstances throughout the lifecycle. Future planning was perceived as a sensitive whole family issue. Interdependence among members was key to retaining family independence from formal services that were regarded as a “top up”. Suggested is the importance of services adopting a relational approach to understanding family care and supporting future planning for middle-aged people with intellectual disabilities, rather than simply focusing on “older carers”.

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International Journal of Disability, Development and Education
Special Issue: Parent, Family, and Professional Relationships
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Commentary: Some Thoughts on the Evolving Arena of Autism Services
Glen Dunlap
The Government committed almost $200million to help autistic children yesterday with a range of measures for parents, new Medicare funding and the promise of hundreds of playgroups across the country. Prime Minister John Howard led a string of ministers in making the announcement yesterday morning, unfazed by Labor simultaneously announcing a pledge for six autism-specific centres. The centrepiece of the Government package is new funding of $116 million over five years for greater access to early intervention on Autism Spectrum Disorders.

Mr Howard emphasised that research was increasingly showing that such intervention was "absolutely fundamental" to boosting the chances of four- to six-year-olds with autism getting into primary school. "There are approximately 15,000 families of children aged up to six years," Mr Howard said. "Now this early intervention is expensive and critical and parents do need help."

A complete individual assessment can currently cost about $800 to $900. "I do know of people who have been in a financial position to do it, they've had very intensive early intervention services and that has made an enormous difference," Mr Howard said. "But not everybody, indeed most people are not able to afford that."

Autism affects one in every 160 children aged between six and 12, making it more widespread than many in the community might have believed. The new deal provides for about 200 playgroups, catering for about 8000 children by 2012. "That will be a wonderful medium, a vehicle through which people can share the burden and in that process develop greater insights and greater understanding," Mr Howard said.

The package provides also for one-on-one and other more intense programs for up to 4000 children and also for individual assistance of up to $20,000 over two years for the families of the 1200 most severely affected children.

On top of this, $20 million has been set aside over five years from July 1 for new Medicare-funded services for diagnosis and early intervention.

Opposition Leader Kevin Rudd praised the Medicare funding for
diagnosis and other aspects of the Government package.
"Autism is above and beyond party politics and I think it's very important that Mr Howard's initiative is combined with ours to provide a total national response to the challenge of autism right across our country."
Labor aims to establish specialised child-care and early-intervention services, concentrating on an "autism-specific approach".
Mr Rudd said, "Our proposal is for a network of six autism centres across the country to assist in the provision of intensive autism-related services.
"Often when you've got someone who is diagnosed with autism, there are a whole range of developmental needs, a whole range of occupational therapy needs, a whole range of speech therapy needs which need to be deployed early. And what we are seeking with these particular centres is to focus on children of preschool age."
Of the simultaneous announcements, Mr Rudd said, "Sometimes in politics, you know, great minds think alike ... the bottom line here is it's good policy for the nation to combine these efforts to help the kids and the carers deal with this challenge."
Eden-Monaro MP and Special Minister of State Gary Nairn, who announced the Government package in Queanbeyan yesterday, suggested the Labor statement was coincidence at best but more likely another case of "me-tooism".
"The detail in this particular [Government] package is not something that could be cobbled together in a few days," he said. "This has been going on for some time."
The Australian Medical Association welcomed "the recognition by both major political parties that the incidence of Autism Spectrum Disorders is a problem that needs appropriate services".
The chair of the association's child and youth health committee, Dr David Thomas, said all forms of ASD autism, Asperger's and language disorder were increasing.
The Australian Association of Occupational Therapists welcomed the Government announcement, saying it would increase parents' access to appropriate professionals.
President Carol Crocker said, "Therapeutic interventions are often more effective and less costly than medication alone."
Better housing options for the disabled
October 5, 2007
The Sydney Morning Herald

Disabled people will have better lives under a creative new model of group housing, the NSW government says.

A two-year trial of "supported" accommodation encouraging greater social interaction will be part of a 10-year plan focused on providing flexible housing options, Disability Services Minister Kristina Keneally said.

"An intentional community allows people with a disability, their families and carers to be involved in the everyday decision making, management and operation of their accommodation and support services," Ms Keneally said.

"The members of an intentional community usually hold common interests such as social activities, cultural links and religious beliefs.

"It can also create a pathway for home ownership or long-term tenancy within a supportive and sustainable community environment.

"That is why we will trial this Intentional Communities model for two years which aims to provide residents with a much higher degree of social interaction."

The government will support the trial by $760,000 a year, Ms Keneally said.

The Department of Ageing, Disability and Home Care has advertised for expressions of interest from service providers to offer "creative accommodation and support proposals".

More information is available at www.dadhc.nsw.gov.au/tenders and successful service providers will be selected using the standard government tender procedure.

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A new federal political party, the Carers Alliance, set up by parents of children with disabilities, will be launched in Sydney this weekend.

Senate candidate, Mary Lou Carter, who's 16-year-old son is severely disabled, said the party aims to bring issues affecting family carers into the political agenda.

"We feel that only by getting a political voice where it counts, in the parliament, will there ever be change for people with disabilities and the people who provide care for them," she told ABC radio.

Ms Carter said there are around 2.6 million carers in Australia who look after people with mental disabilities, with chronic illness or who are aged.

"There are about 2.6 million carers and I'm sure that all of them have at least one other family member and all of them have friends.

"This an issue ... that crosses all borders because disability, mental illness, frail aged, chronic illness knows no socio-economic boundaries."

Party advocate, Katrina Clark, who left her job as a lawyer three years ago to look after her 10 year-old severely disabled daughter, said a major issue is a shortfall of government funding for disabilities.

"What we are saying is there needs to be an enormous injection of funds by the federal government because at the moment there is not nearly enough for equipment for kids with disabilities, for the therapy service that kids with disabilities need," Ms Clark told ABC radio.

"One of the main objectives that we have is to ensure that there's enough long-term supportive accommodation."
CARERS of people with disabilities and mental illness have become a focus of both major and minor parties in the lead-up to the federal election.

The Government will today announce more than $35 million in funding to build and expand respite services for people with severe mental illness/psychiatric disability, people with intellectual disability, and their carers.

Minister for Community Services Nigel Scullion, who will make the announcement, says the money will give 52 organisations across Australia more flexible options, including creating and expanding respite centres, training and paying respite workers, and funding 24-hour, flexible in-home assistance.

Opposition Leader Kevin Rudd has also examined the need for the expansion of respite services, and is expected to announce further policies.

Family First leader Steve Fielding has aimed to appear sensitive to carers, proposing that all full-time primary carers of people with disabilities get four weeks' paid annual leave.

He said the program would cost taxpayers $454 million annually and 105,000 carers would be eligible to receive the payment. The proposed payment of $4320 a month would be used to pay for respite care while the carer takes annual leave.

"Currently, only parent carers over the age of 70 are eligible for up to four weeks' annual respite," he said. "Other carers get respite only if there is money left over, which is a disgrace."

Meanwhile, a new political party to represent Australia's 2.6 million disability carers, the Carers Alliance — which is running candidates in all states except SA and WA — was launched in Sydney yesterday.
A MOTHER has provoked an ethical row by obtaining the backing of doctors to remove her disabled teenage daughter's womb to improve her "quality of life" in adulthood.

Alison Thorpe said her daughter, Katie, 15, who cannot walk or talk and needs around-the-clock care, will suffer undue pain, confusion and indignity by the onset of womanhood.

She wants surgeons to carry out a hysterectomy to save her daughter - who she says has no prospect of having a baby - from the distress and inconvenience of menstruating.

A consultant at her local hospital has taken up her cause and is seeking legal approval to carry out the procedure even though it is not medically necessary.

The move, which follows the case of a disabled American girl who underwent similar surgery at the request of her parents to prevent her "growing up", was condemned on Sunday by disabled rights groups, which said it was wrong to carry out operations for "social reasons".

But Ms Thorpe, 45, from Billericay, Essex, who has another daughter, aged 11, believes she has made the right choice.

She said on Sunday: "It was an agonising decision. As with every decision, I questioned myself endlessly, 'Am I doing the right thing?'

"It is a decision I made probably about two years ago. The operation would prevent her going through the mood swings, the discomfort and the indignity of it all.

"The only opposition has been from disabled rights movements, but I would say to them, 'Come and spend a week with me. Walk in my shoes.'"

Katie is dependent on Ms Thorpe and her partner, Peter Reynolds.
"She is doubly incontinent, she has no useful function in her hands or legs, she can't communicate. Katie has an undignified enough life without the added indignity of menstruation, Ms Thorpe said.

"She will not understand what is happening to her body and it could be very frightening for her."

She said she had the backing of Phil Robarts, a consultant gynaecologist from St John's Hospital in Chelmsford.

Mr Robarts told a Sunday newspaper that he had a good case for getting legal permission to proceed with the surgery.

Disabled rights groups were furious at the move.

"It is unacceptable that doctors want to remove a girl's womb simply because of being disabled," said Simone Aspis, of the British Disabled People's Council. "Katie has the right to grow up with her body intact, and where she can have the same choice as anyone else to give birth to her own children. Katie's human rights are being taken away. This is wrong."

Andy Rickell, an executive director at Scope, a charity, said it was difficult to see how such surgery could be in her best interests, and that Scope did not believe "that a child should be modified to fit society but instead that society needs to adapt and become more inclusive of disabled people".

Telegraph, London
Man jailed over death of disabled worker

October 12, 2007
The Age

A 22-year-old man involved in the killing of an intellectually disabled charity worker in central western NSW has been sentenced to six years' jail.

Nathaniel David Charman, of Blayney, near Orange, pleaded guilty earlier this year to the manslaughter of Michael Joseph Healy, 57, during a bungled home invasion in 2006.

Mr Healy, who was intellectually disabled and a much-loved member of the community, died after being bashed with a heavy metal torch.

Charman admitted he travelled to Mr Healy's house in Orange with two other men on March 11 last year, but said he did not go inside with them.

He said the other two had killed Mr Healy while trying to "knock him out" with a heavy torch, and he had acted as the getaway driver.

The group falsely believed Mr Healy had $60,000 in a safe, along with documents relating to a fraud investigation, which another person, who cannot be named for legal reasons, wanted destroyed.

Sentencing Charman in the NSW Supreme Court in Sydney on Friday, Justice Robert Hulme said he was not persuaded he was of good character because he had "too readily agreed to participate in a home invasion and theft".

In his favour, however, was the fact "he did not strike the fatal blows, and that what occurred ... is not what would commonly be expected to flow from an intention merely to knock someone out".

Charman, described as "a follower", had told a psychologist he had participated in the crime because he wanted to "help friends who had financial problems".

Mr Healy's body was discovered on the floor of his bedroom three days after the
botched burglary, when concerned neighbours contacted police.

Justice Hulme said the crime scene suggested the charity worker had been attacked "whilst lying in bed".

Although Charman did not enter Mr Healy's house in Wisteria Place, his fingerprints were found on the front door, the court heard in sentencing submissions last month.

Justice Hulme ordered a non-parole period of four years, meaning Charman will be eligible for release in April 2010.

On hearing his sentence Charman, dressed in prison greens, nodded to his family members before being led from the court.

His mother broke down crying and was comforted by relatives.

Two other men charged with murdering Mr Healy are due to face Orange Local Court next week.

Another man is due to appear in the same court on the same date on a manslaughter charge.

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Partnership creates jobs for disabled
By Emily Sherlock
Sunday Canberra Times
14 October 2007

BACKED by $75,000 of Federal Government funding, a partnership has been struck between one of Canberra’s largest water companies and a well-known disability service.

Canberra-based grey water re-use company Perpetual Water and an amalgamation of several Canberra disability companies, LEAD, have formed a business partnership which will see staff provided by LEAD manage a warehouse for Perpetual Water.

The staff will help process and fill customer orders including arranging postage for interstate items and hand-delivering in the ACT.

LEAD chief executive Keryl Neville said the funding – applied for under the Australian Government’s Cross Sector Initiatives Program – was a fantastic way to expand employment opportunities for those in the area with disabilities.

“Perpetual water is a relatively new business with great ethics and morals and we are happy to be working with them to expand the scope of employment we can offer,” she said.

The partnership will see about 15 to 25 people with disabilities contribute to the business – the equivalent of five full-time jobs.

Perpetual Water was also pleased with the partnership, managing director John Grimes said.

“We’ve been steadily building our relationship with LEAD for the past three years …so we are thrilled to provide this opportunity for their staffing service to become an integral part of our business operations.

“Through our participation we want to encourage other businesses and services to consider trying a partnership like this for themselves.”

Workers could start work at the warehouse site as early as November.
Blind triathlete breaks two-hour barrier
October 15, 2007
The Sydney Morning Herald

Aaron Scheidies became the first blind triathlete to finish an Olympic-distance triathlon in under two hours on Sunday, finishing the US Open Triathlon in 1 hour, 58 minutes and 8 seconds.

The 25-year-old Scheidies and guide Ben Collins crossed the finish line 48th overall, about 14 minutes behind winner and Australian Olympian Greg Bennett.

The field of about 1,100 included 41 professional triathletes.

"I'm ecstatic," Scheidies said. "Not necessarily because of what I did, but I wanted to prove to general society that people with disabilities can do things better than able-bodied individuals."

Scheidies, who lives in Seattle, suffers from juvenile macular degeneration, a condition in which the central vision slowly deteriorates. Only 10 per cent of his sight remains.

Legally blind since fourth grade, Scheidies was tethered to Collins for the 1.5 kilometre swim and 10km run. In between, they rode a tandem bike in the 40km cycling leg.

Bennett finished in 1:44.41.

His victory gave him a sweep in the five-race Life Time Fitness Triathlon Series and earned $US420,000 ($A467,000).

American Sarah Haskins won the women's race in 1:55:45.

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Older parents of disabled kids get help
October 16, 2007
Sydney Morning Herald

Older people caring for their disabled children will receive extra help, with the federal government announcing $51 million in funding to be spread across almost 70 private companies.

In Brisbane, Community Services Minister Mal Brough named the non-government organisations which would be part of the New Respite for Older Carers of Children with Disabilities Program.

More than 2,600 older carers would benefit from the three year scheme, supporting parents aged 60 years and over and their children aged over 25.

"Many of these older carers have been caring for a son or daughter with a profound or severe disability for many years, and are now ageing themselves," Mr Brough said in a statement.

"They have expressed concern about what will happen to their children when they are no longer able to provide care and the Howard Government will continue to assist these people."

The $51 million will be distributed to 69 non-government organisations across Australia, through 135 separate programs.

It will enable the expansion of services so there are more in-home and centre-based respite services to help older parents continue their caring role.

"Carers need to be able to sustain their ongoing care responsibilities and take a short term break from their caring role and need support to find time and space to focus on other commitments or personal needs," Mr Brough said.

"This new funding will certainly go a long way towards improving access to respite services for carers in different regions across Australia."
An angry breed: handle with care

Many carers are at odds about how to accommodate the needs of their disabled children, writes Adele Horin.

The Sydney Morning Herald
20th October, 2007

The first thing to be said about Mary Lou Carter's home is that there are bars around the kitchen alcove and a locked door. The next is that there is a glorious harbour view from the waterside deck.

"Look at the lovely place I live in," she says. "But it's what happens behind closed doors that makes our lives almost unbearable."

Carter's son Nicholas, 16, has Angelman syndrome, which means he has the intellectual age of a four-year-old. He has no speech, he has epilepsy, and he never stays still. And though he lives during the week at a special boarding school, he can create havoc in the home on weekends and holidays, starting with ransacking the kitchen.

Carter is one of an angry new breed of parent-carers who have started a political party, the Carers' Alliance, to contest the federal election. She is the first on the Senate ticket, and her friend, Nell Brown, is second.

Brown's daughter Tess, 21, has a diagnosis of intellectual disability and schizophrenia, and right now Tess is lying on the couch in the Carter lounge room, demanding biscuits. "She's on medication that makes her hungry all the time," her mother says, proffering an apple.

Most could empathise with the situation Carter and Brown find themselves in, looking after difficult children who will never grow up. A survey of 4000 carers by Deakin University published this week showed more than one-third suffered severe depression.

Much harder, however, is to walk in the shoes of the one who has the intellectual disability. What is best for them? Therein lies the conflict wracking
the disability movement as it presses claims in the election.

Though it is an idea that is hard to grasp, what is good for the carers may not be good for their sons and daughters. Division is growing between two groups - longtime disability rights advocates whose primary focus is the person with disabilities; and new agitators, such as Carter and Brown, who helped establish the National Carers' Coalition; and Katrina Clark, who has started the Association for Children with a Disability. Their mission is to give carers a louder voice.

To longtime disability right advocates, many who are parents of disabled children, the newcomers represent a backlash. They threaten to shift focus from the rights of people with disabilities to the interests of carers. "In the battle to focus on the rights of people with disabilities, we've lost 30 years of ground," says Matthew Bowden, co-chief executive of People with Disabilities, an advocacy group that began 26 years ago.

The way newcomers frame the debate offends many longtime disability advocates. They make frequent reference to their lives as "unbearable" and to their children as "burdens". For example, an angry submission by the National Carers' Coalition to a Senate inquiry into disability funding last year talks of "families saddled with this burden unaided", "lifelong suffering", and "servitude", and urges the Government to examine the "sham that is the 'community inclusion' rhetoric".

Belinda Epstein-Frisch, a spokeswoman for Family Advocacy, a group that has long helped families with disabled children, says: "I find it very offensive to have issues represented in this way. I don't consider my daughter a burden."

On the other hand, to say the new breed feels let down by the established disability rights groups, such as People with Disabilities, and Family Advocacy, is an understatement. As well, they do not feel the established carers' organisation, Carers' Australia, has represented their interests effectively. These are women who feel thwarted in their careers, isolated in their social lives, and angry that promised services, especially accommodation for adult children, usually did not materialise.

Katrina Clark, whose 10-year-old daughter is severely disabled, says: "At
consultations with parents two or three years ago I saw 70-year-olds stand up and say, 'I'm looking after my son or daughter at home.' There's no way that that will be me."

The depth of the antipathy between carers and people with disabilities was apparent when the National Carers' Coalition made a Senate submission for funding of parent advocacy groups saying, "We are denied the same privileges as are enjoyed by disabled persons themselves through a network of national, state and regional advocacy services".

But the new activists hotly deny they put their own interests ahead of their children's. They do not believe there is a conflict.

"Families love their sons and daughters, and no one wants to do anything that will harm them," Brown says.

In its impact on society, the disability rights movement has been as momentous as the women's movement. In the past 30 years it has powered a radical shift in focus: from care and protection of people with disabilities to promotion of their rights and equality. At heart is the principle that people with disabilities have a right to live as normal a life as possible in the community and the chance to fulfil their potential. Antidiscrimination laws followed.

The iconic issue has been accommodation. The "disability gulags" - institutions which housed together scores, even hundreds, of people with disabilities - symbolised all that was wrong with past policy. The fight to close institutions has been waged at times in the teeth of parental opposition. People with disabilities should not be hidden away, and forced to live en masse, the rights activists argued. They should have options like everyone else, to live with their family, and later, as adults, to live with friends, housemates, partners, or by themselves.

To realise this ambition, of course, the State would have to help. It would have to fund the paid support staff, and sometimes the bricks and mortar, needed to make it possible. Thousands of people with disabilities in NSW have been given the chance to flower by living in small group homes, with staff to help facilitate activities and integration into normal life. But the lucky ones are the tip of an
Carter, 52, is a wiry dynamo, all nervous energy and passionate talk. She is married to a lawyer and has another son, David, 22, a law student, who makes the visitors cups of tea, and answers the constantly ringing phone. Carers are phoning in to offer support for the Senate campaign - or to beg off because of a family crisis.

Brown, 51, is divorced with three adult children who have left home. She lives with Tess on a government benefit. She became politicised four years ago after the State Government planned to cut funds to a post-school disability program.

"We are the first generation," Brown says, "who not only kept their kids at home but did so when other women were in the workforce. I'm ageing without assets or superannuation. Families chose whether they wanted to care before. Now there is no choice."

It is ironic that what has exacerbated the divisions between disability rights advocates and carer groups is the first decent injection of government funds into disability services for decades. After years of neglect the State Government last year committed $1.3 billion over five years to disabilities services, including for housing.

And in this election year the Federal Government has come to the party for the first time, offering $1.8 billion for long-term housing, limited to those with elderly parents. But what sort of housing is on offer? This is the nub of the dispute between the two sides.

It is not the group homes, with no more than five housemates, or flats, or co-tenancies, with support staff, that most resemble "normal" life.

A cheaper model is being proposed - "congregate care" or cluster housing where 10, 20, and in one case 60 people with disabilities will live together. To the disability rights advocates these are "mini-institutions" hardly better than the old gulags. A similar experiment in Britain failed. An evaluation by Professor Eric Emerson, of Lancaster University, showed a much poorer quality of life for those in cluster housing compared with those in the dispersed small-group homes.
Those in the big clusters were supported by fewer staff, more likely to lead sedentary lives, and participated in fewer leisure and friendship activities. Seclusion, sedation and physical restraints were also more likely for them, Professor Emerson reported.

Christine Regan, vice-chair of the Council for Intellectual Disability, whose daughter Erin, 30, still lives with her, understands the fears and anxieties of parents.

She had thought her daughter, who has Down syndrome, and then suffered a stroke, might be living independently by now, perhaps in one of the houses with support staff that Regan was instrumental in establishing. But 21 years later she is well down the waiting list.

"My needs as a carer are critical," Regan says. "But they are second to my daughter's needs. I am waiting for my daughter to get the support she needs rather than shove her into something that will not be acceptable.

"We know larger groups don't provide the same good outcomes as dispersed community living. They are a slightly 'less-worse' institution."

As the sun shines on Sydney Harbour, and Tess gets the biscuit she coveted, the conversation in the Carter household shifts to the proposed new housing models.

To Carter and Brown these housing proposals sound like pleasant villas, no different from "gated communities" where wealthy people might live. "It's not the size of the roof that counts," Carter says. "Abuse and neglect can happen in a group home."

Brown calls the proposed congregate care models "intentional communities" where people with disabilities can share their lives with each other.

The women believe people with disabilities can be legitimate communities, like migrants who gather together because they understand each other. And this led Carter recently to lend her support to a successful parent-led campaign to reverse the closure of an institution, Weemala, in the Prime Minister's electorate of Bennelong.
Closing Weemala would "fracture the community", Carter believed. John Howard and Labor's candidate, Maxine McKew, sided with the parents while disability rights activists watched horrified as long-held plans to move all the residents into the community unravelled.

On all sides in the disability community there is furious agreement on one issue: the need for more money. In particular there is a push for the Federal Government to fund disability accommodation according to a formula of need, as it does with aged care.

While the rights activists stand their ground, and fight for principles, Brown asks: "Who have they been fighting for? Maybe 5000 people in this state have got group homes. You can't say they've created the dream."
Small is beautiful: words come at home

Adele Horin
October 20, 2007
Sydney Morning Herald

FOR 39 years Mario Trovato lived in the Sunshine Home, an institution for people with intellectual disabilities. He never spoke a word in all that time. A grunt passed for 'no' and that seemed to sum up his attitude to life.

"He understood but he was unco-operative," said Teresa Avedillo, the staff member charged with his care for 10 years.

"You would ask him to take the rubbish out and he'd run and hide. If he was angry he would turn the tables upside down and throw chairs at staff."

Sunshine Home, run by a charity with government funding, has cared for people with disabilities since 1924. At its peak in the early 1980s, more than 200 people lived on the two-hectare site at Gore Hill. But after the Richmond report in 1983 cast doubt on the benefit of institutional care, the Sunshine Home board reassessed its philosophy. It refused to take new entrants, and started buying suburban houses. Around the world, the disability rights movement was taking off.

By the time Mr Trovato was moved into a two-storey house in Glenwood with four other men on Australia Day 2005, there was hardly a soul left in the institution. Nearly all had moved into group homes of four or five housemates. His was not the easiest transition, despite years of preparation. On visits back to the Gore Hill site, where there was a sheltered workshop, he would drift back to his old abode and refuse to get into the van.

"It took maybe a couple of months for him to settle," said Ms Avedillo, who had moved along with the residents.

She was cooking sweet and sour fish one night and a delicious aroma filled the kitchen. Mr Trovato opened the oven door. "Beautiful," he said.
Ms Avedillo was amazed. She laughed, she demanded he say it again. "Beautiful," he replied. At the age of 44, Mr Trovato had spoken his first word. Soon after he came to her and said, "atv abroke abuy anew". His faulty television had prompted his first attempt at a sentence.

"I looked at him and I said, 'This is what I want. I want you to tell me what you need, and I can help you out,'" Ms Avedillo said.

Mr Trovato's life has changed dramatically since he went to the house, his sister Sandy says. "There were too many people and not enough attention before. Now he goes out, he wants to talk. He says my name. It's amazing."

His aggressive behaviour has ceased, he helps with chores. All the housemates have a say in weekend activities and the menu.

For disability rights advocates, Mr Trovato's transformation is proof that people with disabilities benefit when given the chance of a normal life in the community in a small group home. But as Mr Trovato gets on with his new life, a feud has split disability advocates. A new band of angry parents, who mostly have looked after their disabled children at home, are fed up with waiting for the Government to fund enough group homes. They have lent support to new state and federal government plans to provide cheaper housing options where 10, 20 or more people with disabilities might live together.

To longtime disability activists, these planned facilities are "mini-institutions" that threaten to swallow a new generation, and turn the clock back 30 years.

Sunshine Home's chief executive, Rebecca Fletcher, says the benefits of group homes are enormous. But it is an expensive option. "I am a realist," she says. "If the money is not there, you can't rely on philosophy."
Aged big winners in $4b coalition plan

October 23, 2007
The Age

Aged pensioners, carers and those with a disability will be given a $500 annual allowance if the federal coalition is re-elected on November 24.

Prime Minister John Howard visited the marginal Liberal held seat of Kingston in South Australia on Tuesday to announce the $4 billion plan.

Under the plan the utilities allowance will be extended to an extra 820,000 people, and increased from $107.20 a year to $500.

The utilities allowance is currently paid annually to aged pensioners, and provides support to meet household bills including power and gas.

Mr Howard plans to extend the allowance to 700,000 people with disabilities and 120,000 carers.

"Any fair-minded Australian will think that we can afford, as a nation, this additional help to carers," Mr Howard told an invited crowd at Adelaide's Morphett Vale Memorial Bowling Club.

"There has to be a social dividend of prosperity."

Opposition Leader Kevin Rudd cautiously welcomed the plan.

"Pensioners and carers need all the support that we can give them, but we need to go through the detail and you'll have our policy on this well before the election," he told reporters in Sydney.

When pressed he refused to immediately endorse the initiative.

"It's a significant amount of money, and therefore I want to look at it carefully."

Mr Howard's plan doesn't stop at helping pensioners, he also wants to give more
money to self-funded retirees.

Part of the $4 billion will go to more than doubling the state government-based public transport concession scheme which is available to all senior citizens.

"The allowance recognises that most self-funded retirees do not receive the concessions on energy, rates and motor vehicle registration that pensioners receive."

Despite making the announcement in the middle of an election campaign, Mr Howard declared the policy a "commitment of government" which had been made prior to the coalition moving into caretaker mode.

He did, however, admit legislation would have to be passed for the scheme to become official.

The $4 billion comes on top of Sunday night's promise by Mr Howard to offset the higher cost of electricity for pensioners once a carbon emissions trading scheme comes into force in 2011.

But Greens leader Bob Brown said Mr Howard's $8 a week increase for pensioners was a pittance next to his own $150-a-week tax cut.

"John Howard's going to give himself over $150 a week tax cut and he's giving the pensioners and battlers on the lower income scale less than $8 a week," Senator Brown said in Sydney.

"His $8 a week is pensioner tokenism ... Pensioners are hurting, they're in poverty and less than $8 per week is not going to keep up with the increasing cost of transport, of food, of health that people are facing."

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$500 extra, but carers just want some dignity

The Age
October 24, 2007
By Leo Shanahan

For Lyn and Victoria Dowd, it is a question of dignity. The dignity not just to survive on what they get as a carer and a disabled person, but to have a standard of living similar to others who do not suffer their daily burdens.

"Someone should have the basic dignity, of sitting comfortably, looking appropriate and not having the extra burden of worrying about the money," says Lyn Dowd.

Mrs Dowd, who is the sole carer for her 28-year-old daughter who is confined to a wheelchair and severely disabled with cerebral palsy and joint disease, has welcomed the attention that the Government's $500-a-year utilities allowance has brought to carers. But she says the benefit will be marginal.

"The reality is it equates to $10 a week and it's not in the world of reality . . . My carer payment is $49 a week that's for a 24/7 job. If I walked out the door now, Victoria would die," says Mrs Dowd.

Mrs Dowd has looked after Victoria by herself for 27 years after her husband died in an accident the same year Victoria was born.

She says that there should be more government money put into quality, long-term accommodation for the disabled as well as proper payment for carers.

"I challenge any minister to do what I do for a weekend. I would like a fair day's pay for a fair day's work and the dignity that goes with that. Because at the moment there is no dignity whatsoever."

While Victoria receives a disability pension that goes a minimal way towards her living costs, Mrs Dowd gets by on home-based jobs.

"I've been on a pension, but you can't survive on it."
The extra costs of caring for someone severely disabled are often more extreme because of the equipment costs that go with it.

Mrs Dowd waves around a receipt lying on the kitchen table.

"These are for her shoes: $1100 for a pair of her special shoes, and these are the cheap ones."
We have seen promises for families of children who have autism. We have seen promises for young carers, for ageing carers of adults who are more than 40 for a disability accommodation support program. We have seen much made about family carer issues. We have promises for more money for parents of young children, funding for 50 per cent payment for computers for schoolchildren and now money to help with utilities for carers and people who have a disability. I could go on and on.

Unfortunately for people with disability who are over school age and under 40, or who have parents between about 35 and 65, there is nothing. The Senate inquiry in the Commonwealth States and Territories Disability Agreement identified, among 29 key recommendations, the primary recommendation that the federal, state and territory governments jointly commit additional funding to address identified unmet need for specialist disability services, particularly for accommodation services and support.

The Federal Government offered to match whatever the states could put up. South Australia was one state which did not provide the numbers for matching. The Federal Government promptly withdrew its offer. People with disability are still waiting for the next disability agreement to be signed and for recommended "substantial additional funding" to be committed to enable them to have a reasonable level of support.

While all levels of government play the "I said, you said" game, some people can't get a shower, get out of bed or have their home cleaned and, just as importantly, can't have support to get out and about. Many parents cannot get even a couple of hours a week in or away from home support.

The South Australian Council on Intellectual Disability wants to see policies about a "substantial increase" in funding for support and services for people
with disability. If they are well supported, there would then be less need for families to be propped up with one-off or once a year payments.

Fund the person and stop exploiting family carers by holding out little carrots to keep them keeping on until they drop.

**Delphine K. Stagg** SA Council on Intellectual Disability Inc, Holme (SA)
National Council on Intellectual Disability

Federal Election – Media Statement

People with intellectual disability demand quality support

In 1992, the signing of the first Commonwealth State and Territory Disability Agreement (CSDA), enshrined funding for accommodation support as a joint responsibility of both levels of Government. Since then, however, the commitment of the Commonwealth has lagged far behind that of the States and Territories, and we have seen successive Federal Ministers cynically abrogating Federal responsibility. In contempt of the CSTDA, they have continually claimed funding for accommodation support as solely a “State and Territory responsibility”.

The recent offer by the Commonwealth to match the States and Territories 50/50 on funding for unmet need was the first sign the Howard Government might be prepared to fulfill its responsibilities, and was welcomed as such by NCID. However, the peremptory withdrawal of this offer by the Government and the refusal of the Labor Opposition to pledge its reinstatement exposes both major national political parties as being disinterested in the needs of people with disability and their families.

NCID deplores the political buck-passing associated with the current CSTDA process. We condemn the Federal Government’s plans to administer selected accommodation services without reference to the States and Territories as being a major step backward. We demand greater accountability and transparency from the States and Territories in their administration of disability support funding. We condemn the politicisation of disability issues by both levels of Government.

People with intellectual disability and their families need:

1. A CSTDA that fully funds quality supports to people with a disability and their families on a 50/50 shared Commonwealth and State-Territory basis.
2. A CSTDA that provides for the effective and efficient administration of funds by each State and Territory.
3. A CSTDA that is devoted to achieving quality outcomes, and which adopts evidence based research to guide the way.
4. A CSTDA that fosters positive and cooperative relationships between all levels of government.

NCID calls upon all parties contesting the next Federal election to respond to this demand.
The National Council on Intellectual Disability (NCID) was established over 30 years ago by parents and friends in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, i.e., our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with intellectual disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.