

*i*nteraction

VOLUME 18 ISSUE 2 2004



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Part II: The Australian Experience
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- Bruce's Story and a Poem
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- Criminal Justice & Indigenous
People with Cognitive Disability

The Australian Institute on Intellectual Disability

The Australian Institute on Intellectual Disability (AIID) operates as the information, research and development arm of NCID. The AIID is entering into a new and exciting phase that will see it expand its current role of delivering information to people with intellectual disability, their families, service providers and the broader community.

The AIID aims to support high level, high quality, independent analysis and strategic policy advice in order to improve the effectiveness of disability service systems, and help sharpen the focus of groups advocating for reform and improvement.

The activities of the AIID include:

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i Editorial

I spend a great deal of my time listening and reading, and at times inspiration and clear ideas come from unsuspected sources. I was listening to the radio in November when the Sydney Peace Prize lecture by Arundhati Roy came on. Two elements of her speech in particular made an impact on me and made me think about the editorial in the last issue of *Interaction*.

Today, it is not merely justice itself, but the idea of justice that is under attack. The assault on vulnerable, fragile sections of society is at once so complete, so cruel and so clever - all encompassing and yet specifically targeted, blatantly brutal and yet unbelievably insidious - that its sheer audacity has eroded our definition of justice. It has forced us to lower our sights, and curtail our expectations. Even among the well-intentioned, the expansive, magnificent concept of justice is gradually being substituted with the reduced, far more fragile discourse of 'human rights'.

If you think about it, this is an alarming shift of paradigm. The difference is that notions of equality, of parity have been pried loose and eased out of the equation. It's a process of attrition. Almost unconsciously, we begin to think of justice for the rich and human rights for the poor.

Peace & The New Corporate Liberation Theology

The 2004 Sydney Peace Prize lecture delivered by Arundhati Roy,
at the Seymour Theatre Centre, University of Sydney.

In particular, two phrases will resonate with people with disability and their families, "(D)t has forced us to lower our sights, and curtail our expectations" and "(T)he difference is that notions of equality, of parity have been pried loose and eased out of the equation". For many years, we have spoken about the need for people with disability to have their most basic 'human rights' met -- in particular, their (human) right to housing and daily living support. All people with disability and their families know that there is a huge unmet need that is ignored by politicians and bureaucrats. And, far from addressing this need through planning and the provision of resources, we have politicians and bureaucrats making statements like:

- 'the 'problem' (sic) is too big -- we can never meet the need'
- 'people have too high expectations'
- 'those who have services are going to have to have less if more people are to receive services'
- 'we cannot provide Rolls Royce services'
- 'there is not enough money to go round'
- 'the government already spends X million of dollars, what more do people want?'
- 'we can provide a basic service for a lot of people or good quality services for some'
- etc, etc

It would appear that we as a community have lost the ideal of 'a fair go'. The idea of equality has become a luxury, and like all luxuries is only available to those who have. The question is how much is this 'our fault'. By accepting the (lesser) concept of human rights, instead of

insisting on our right to justice, we may be providing an excuse for politicians and bureaucrats to treat people with disability and their families as second class citizens. The obligations and responsibilities that governments have to all their citizens must be enshrined in legislation to ensure that all citizens are treated with equality; to ensure that people with disability and their families are provided with the resources they need to have good quality support services as a right as a citizen.

On a more positive note, a second section of Arundhati Roy's lecture that struck me was:

The good news is that the advance party began the climb some time ago. They're already half way up. Thousands of activists across the world have been hard at work preparing footholds and securing the ropes to make it easier for the rest of us. There isn't only one path up. There are hundreds of ways of doing it. There are hundreds of battles being fought around the world that need your skills, your minds, your resources. No battle is irrelevant. No victory is too small.

Peace & The New Corporate Liberation Theology

The 2004 Sydney Peace Prize lecture delivered by Arundhati Roy,
at the Seymour Theatre Centre, University of Sydney.

Though, talking about being "trapped between the horror of a putative peace and the terror of war. Those are the two sheer cliffs we're hemmed in by. The question is: How do we climb out of this crevasse?" This paragraph vividly gave me a picture of thousands of people with disability and their families over the decades working for a better future. And, in these times of great stress for the many families who are struggling to get the support they desperately need, it is important for us to remind ourselves and each other that:

"No battle is irrelevant. No victory is too small."

Mark Pattison
Executive Officer, NCID

PS. This editorial does not in anyway endorse the central arguments of Peace & The New Corporate Liberation Theology -- readers must draw their own conclusions.

Letters to the Editor

Friday, 3 September 2004

Dear Sir:

I have read with interest the articles on “inclusion” in education in recent editions of your magazine.

As a teacher and mother of a supposedly autistic child, I am saddened to see that now, over 40 years after the diagnosis of our son, Bruce, authorities have come round to what I tried very hard to have happen for him when he first started school all those years ago.

In particular, I note now that parents are seen as a vital partner in education, whereas all those years ago, we were treated as though we were similarly intellectually disabled, even though both parents had gone to selective high schools for talented children. I note also the scepticism of reliance on the medical model as the basis of an educational placement. In our case, I am sure that delegating Bruce to the newly opened school for autistic children was a matter of convenience for the Department of Education at the time which was closing down its classes for children with specific learning difficulties.

I have always maintained that, had Bruce been included in a normal class, his speech would have improved as well as his social interactions. The Doctor who diagnosed him, a Dr. June Maloney, was very irate when I suggested this and demanded of me if I did not think she knew what she was doing, being the expert in intellectual disability. I have often reflected on the ambiguity of her comment, to say nothing of its arrogance.

Years later, at age 72, I completed a Diploma in Welfare following earlier studies in Education.

The enclosed is a shortened version of a study we were required to do for Society and Culture, viz, “walking in the shoes” of someone disadvantaged in our society. It is Bruce’s story, from his point view, with obviously many things omitted which only Bruce has experienced over the years when he was pushed in and out of various institutions as a result of Dr. Maloney’s inept, insensitive diagnosis and the ignoring of his mother’s point of view. Perhaps you might publish it. The poem is my projection of his perception of the world.

Yours truly

(Ms) Kate Thomas, J.P.B.A.Dip.Tch.M.Ed.Dip.Welfare

Editor’s note:

We are delighted to publish both the poem and Bruce’s story. Please go to pages 19-24 in this edition of *Interaction*.

LIVES UNREALISED

An Essay on Society's Responses to Disability

Rob Westcott

PART 2: THE AUSTRALIAN EXPERIENCE

(continued from Part I in *Interaction* Volume 18#1)

As North America adopted European practices in relation to the mad and feeble-minded, so did Australia look to both for guidance. While there is no evidence that anyone transported on the First Fleet had significant congenital or other disabilities, it is entirely possible that some did, given the squalid and poverty-stricken urban environments from whence they came. In the late Eighteenth Century, less privileged areas of London and other urban centres generated their own form of bedlam. Typhus, dysentery and assorted fevers were rampant. Human and animal waste was left in the streets to pile up in cesspools, which then leaked into wells. Crime was endemic. Street gangs, vagrancy and licentiousness defined daily life. From this world emerged petty criminals made yet more wretched by pitiless imprisonment once apprehended, and transportation among other penalties, once convicted. There was little to distinguish one lost soul from another. Lunacy and feeble-mindedness could readily blend into the mainstream.

Among those who arrived in the new colony in the next few years were a number of people deemed insane, some as a consequence of the callous treatment they had to endure. The worst social nuisances were physically confined. Severe punishments awaited anyone who stole or committed anti-social acts, particularly those involving theft or violence. But a strange and colourful mixture of characters typified Australia's early white population, giving birth to the myth of the laconic larrikin. A certain egalitarianism and tolerance of people who were harmlessly different was evident because everything about the new colony was different. Conformity to the social mores set by Britain and civilisation was for the authorities. For others, survival was all that mattered.

By 1811, there was sufficient concern at the number of seriously insane and infirm people wandering the streets of Sydney Town unchecked, or languishing in the Parramatta gaol, to warrant the opening of the first mental asylum at Castle Hill. The Government Gazette lauded its opening with:

His Excellency (the Governor), commiserating the unhappy condition of persons labouring under the affliction of mental derangement, has been pleased to order an Asylum to be prepared for their reception at Castle Hill, whither they have been accordingly removed from their former place of confinement which was in the town gaol of Parramatta, and every provision that humanity could suggest has been made for their accommodation and comfort. (NSW Gov. Gazette 1811, cited in Bostock 1951, p.18).

In fact, conditions were soon, if not at the outset, primitive by comparison to those in asylums in Britain and America. While details are sketchy, inmates apparently existed in a manner not unlike their contemporaries in Bethlem Hospital. Keepers' attitudes ensured their charges

experienced the same rough and ready treatment, neglect, and rare compassion. Rusty manacles were unearthed on the site of the asylum long after its demise.

The enlightened approaches adopted at facilities such as the York Retreat were unknown in Australia until a century later. This was despite instructions issued by Governor Macquarie concerning the operation of the Castle Hill Asylum:

- 1) You are hereby ordered and directed to pay the most particular attention to the cleanliness and comfort of the Lunatics placed under your charge, in as far as their unhappy condition and the means you possess will admit of. You will see that they wash their hands and faces every morning and that they shave and put on clean linen every week, namely on Sundays and Thursdays.
- 2) You are not to allow the keepers or other persons attending them to exercise any unnecessary severity towards the Lunatics but see that they are at all times treated with mildness, kindness and humanity. The Keepers and other Attendants are to receive strict orders to this effect.
- 3) You must be particularly careful the provisions issued from the Government stores for the use of the Lunatics are properly dressed and served out to them at proper hours. You must also be very careful that no person shall defraud the Lunatics of any part of the rations allowed them by the Government; a crime which has been here-to-fore very common, and which if ever again committed must be severely punished when detected.
- 4) With a view to promote the health as well as comfort of the Lunatics, you are to get a good garden into cultivation as soon as possible at Castle Hill, in order that they be furnished with a constant supply of vegetables, particularly potatoes and cabbages. Such of them as are fit for manual labour are, with the permission of the Surgeon, to be employed in cultivating the garden thus ordered, as stated every day; which will be the means of not only amusing them, but will likewise prove a wholesome exercise highly beneficial to their health.
- 5) With respect to the medical treatment of the Lunatics placed under your charge, you are to follow and comply with such directions and advice as you may receive from time to time from the Surgeon appointed to attend the Asylum at Castle Hill; and you are on no account to make any of the lunatics work in the garden or elsewhere, without the approbation and sanction of the Surgeon, as he alone is capable of judging whether such labour be good for their health or not.
- 6) You will not fail to report to me in writing, once every month the number and state of the Lunatics under your charge; specifying such casualties, increase or decrease as may have occurred during the preceding month. You are to commence making these monthly reports on the first of the next month of October. (Macquarie, cited in Bostock 1951, p. 21).

Mayhem prevailed despite Governor Macquarie's honourable intentions. As one Surgeon, Parmeter testified to a jury some time later:

I do hereby testify that Francisco, the Deceased Maniac, died from two mortal wounds he received on his head and nape of the neck which were inflicted by some sharp instrument, and which I have every reason to believe from the extent of the wounds to be an axe. Furthermore, from the evidence already given, I am to suppose that Griffiths, a Lunatic, is the perpetrator of the horrible deed. I also declare that the aforesaid Griffiths is an Idiot

not acquired from any decay of memory, but from external causes and finally conceive that Francisco might yet have been alive, had my repeated Regulations (in conformity to His Excellency the Governor's instructions) been attended to ... (Parmeter, cited in Bostock 1951, p. 28).

Castle Hill Asylum closed in 1825 due to the decaying state of the building, lack of water, distance from medical care, and because the Church wished to use the land on which it was located for other purposes. All twenty-seven male and eight female inmates were transferred to the Liverpool Courthouse building and remained there until the opening of the Tarban Creek Asylum at Gladesville in 1838. Later named Gladesville Hospital, it remained in use for a century and a half. By 1844, Tarban Creek accommodated a hundred and forty-eight inmates. A second asylum opened at Parramatta in 1848. By 1869 these facilities accommodated a total of 1155 inmates with a hundred or so having some level of intellectual disability.

Elsewhere in this vast continent, authorities were increasingly pressed to address the issue of lunacy. Incarceration with benign intent but brutal outcomes resulted. Nobody quite knew what to do, so buildings were established but without a clear understanding of how they should function or of the implications of placing numerous troubled people together. In Tasmania, New Norfolk Asylum opened in 1829; in South Australia, the first patients were received at Easter Plains in 1846; and in Victoria, Yarra Bend was established in 1848. Fremantle Asylum opened in Western Australia in 1857 and Woogaroo Asylum in Brisbane in 1864. The numbers accommodated in these facilities were initially in the scores rather than the hundreds and thousands that followed. Some facilities were staffed by gaol warders. In all instances, inmates could expect rough compassion at best, and more usually beatings and other punishments so that overtaxed or incompetent staff could maintain order and control.

At Yarra Bend in Victoria a Committee of Enquiry established four years after the institution was built found:

... these unfortunate creatures have, from the entire absence of any proper supervision ... been subjected to all the coercion and punishment usually had recourse to in Madhouses, at the will and caprice of the uncontrolled Attendants; that the shower bath which should only have been used as a means of improving the physical and mental health of the patients, has been turned into an engine of torture, and cases have been brought before your Committee in which patients with their clothes on, have been locked in the bath ... the 'Strait Jacket', the 'Handcuffs', and the 'Gloves', have been applied at will by the Attendants, who left to themselves the entire day with the exception of a brief morning visit by the Superintendent, seem to have unlimited sway in the institution; and thus from gross mismanagement and the total want of control over the Attendants, the unhappy Patients were much more likely to have their malady hopelessly confirmed, than to have a fair chance afforded them of being cured and restored to society. (Committee of Inquiry 1852, cited in Brothers 1961, p. 23).

The Report detailed other deficits and abuses at Yarra Bend ranging from sexual and physical assaults to misappropriation of funds. Evidence given by inmates included descriptions of cells as lice and flea ridden, smeared with faeces and never cleaned, with dirt floors, damp and soiled bedding, numerous draughts and poor light. A patient who had experienced the conditions at Bethlem Hospital in London, and who subsequently made his way to Australia only to be incarcerated again at Yarra Bend, viewed his antipodean experience as infinitely worse.

During the course of the Inquiry into Yarra Bend, Lieutenant Governor Latrobe appointed Doctor Robert Bowie as Surgeon Superintendent. Despite Bowie's efforts over the next decade, there was little improvement and he was retired in 1862 after more complaints. His legacy included a uniquely Australian method of restraint comprising a blanket lined body-sized canvas bag tied or padlocked at the neck in which a person could be confined yet still retain some limited movement. Patients were kept subdued in this fashion for days and thus left soaked in their own urine and faeces unable to escape the attention of assorted vermin that frequented the institution. Additional asylums were constructed throughout Australia in the latter half of the Nineteenth Century, some in outlying rural areas. Mayday Hills at Beechworth and Aradale at Ararat opened in 1868 and within a few years each accommodated around 400 patients. In Sydney, Rydalmere Mental Hospital accepted its first patients in 1888. Elsewhere in New South Wales, conversion of the old military barracks in Newcastle as an asylum in 1872 was followed by construction of Kenmore Hospital in Goulburn in 1894. Stockton, Peat Island and Morisset Hospitals had opened nearer Sydney by 1910. The Kew Asylum in Melbourne opened in 1872 (eventually to accommodate over 1000 inmates) and Sunbury in 1879. As occurred in New South Wales with the opening of the Newcastle Asylum, Victoria moved to separate mental defectives from the rest of the institutionalised lunatic population. The Ballarat Asylum opened in 1877. Within a year almost two hundred idiots and imbeciles had been transferred there from Yarra Bend, but a year after that were transferred to Sunbury and the Ballarat Asylum closed.

Within a few years, Sunbury was described as accommodating:

... the aged, imbecile and harmless class, drawn from the several lunatic asylums of the colony, and number 227 males and 258 females. There are about 40 in each ward, whose daily lives with the exception of about two days a month, are passed between a dormitory, a day-room, and an exercise yard, enclosed by a close high paling fence. The dayroom, (about 40 feet by 30 feet), is supplied by an ill designed fireplace that affords little or no warmth, while consuming a large quantity of fuel. The exercise yards are so muddy in winter that they are quite unfit to be used, so that for many weeks of the year the only place available to the patients for taking exercise in the open air is a dangerous battened covered way, 100 feet long by 10 feet wide. They never know what it is to have a hot dinner, and for the greater portion of the year it must be absolutely cold, which can be easily understood when it is mentioned that about forty minutes elapses from the time the dinner is dished in the kitchen to the time the patient sits down to it. The water used for the baths is kept in open tanks, and every Thursday the patients get a plunge bath, the temperature of which in winter is so low as to make their immersion in it cruelty...the Board consider that the treatment of the unfortunate patients in this institution is not only ill-adapted to improve their condition, but may be pronounced almost inhuman. (Report c1880, cited in Brothers 1961, p. 126).

The thirty-four staff members at Sunbury were variously described as neglectful, cruel and frequently inebriated. They mistreated patients, refused to obey instructions, and were "failures in life ... placed and maintained here by their political friends" (cited in Brothers 1961, p. 126). Observations of other institutions drew similar conclusions. The pattern was the same everywhere. The problem of lunatics and imbeciles drove governments to establish special facilities as alternatives to incarceration in gaols. They were opened with a fanfare and with precise instructions given regarding the care of their inmates. Within a few years or less, complaints led to Inquiries that confirmed neglect and abuse. Staff members were frequently

replaced and recommendations made to rectify the problems. Yet the deficiencies remained.

Medical treatment in asylums in the Nineteenth Century constituted a mixture of the traditional and the inventive. Emetics and purgatives were in common use as was bleeding and blistering. Cold showers were employed to quieten the agitated, and mercury, digitalis, quinine and opium administered for a variety of complaints. As in European and North American institutions, it was often difficult to differentiate between treatment and punishment. In the 1880's, people could be confined in cages, chained to stakes, caned, secured upright in racks, spread-eagled in box beds with irons attached to wrist and ankle, and have their heads wrapped in scalding blankets. These abuses were regarded and referred to as therapeutic treatment.

Population size and economic and political strength ensured New South Wales and Victoria led the way in the establishment of facilities for the insane. But patterns were similar in the other colonies. Following a Royal Commission in South Australia, a modern institution modelled on the latest developments in Europe and North America was to be opened at Parkside. Lack of funds caused the original project to be abandoned and outmoded facilities continued to be used until 1902. Queensland's Woogaroo Asylum housed almost a thousand inmates by 1889, the overcrowding resulting in appalling conditions. Establishment of smaller asylums in Toowoomba and Ipswich did little to alleviate the problem. In Western Australia, a second asylum was opened at Whitby Falls in 1897 and relieved some pressure on the facility in Fremantle. Conditions were somewhat better because of its rural location. In the early 1900's additional institutions were established throughout Australia including Bloomfield in New South Wales, Janefield, Pleasant Creek and Travancore in Victoria, Claremont in Western Australia, and Strathmont in South Australia.

Legislation concerning lunacy was enacted in all states during the latter half of the Nineteenth Century. In New South Wales, the Dangerous Lunatics Act of 1843 was concerned mostly with the protection of the community from 'persons dangerously insane'. Apart from a minor amendment in 1845, and two subsequent unimportant Acts in the 1860's, legislative provisions remained unchanged in New South Wales until 1878. The Lunacy Act of 1878, and its successor of 1898, were much more comprehensive and specific. Private asylums were to be regulated to ensure humane treatment. There were to be rules concerning notification, admission and discharge of patients, visits to facilities by specially appointed officials, and supervision by medical practitioners.

Other colonies emulated New South Wales. Tasmania in 1858 enacted the Insane Persons Hospital Act with an amended version introduced in 1885. The South Australian Lunacy Act of 1844 was similar to the New South Wales Act of the same period. The subsequent Lunatics Act of 1864 remained in effect until the Mental Defectives Act of 1913. This provided for the compulsory segregation of the mentally deficient. In Victoria, a Lunacy Act was passed in the 1860's, and another in 1888. The Queensland Parliament enacted legislation in 1884, and in Western Australia the Lunacy Act of 1871 was in force until after the turn of the Century.

Most such legislation was concerned with the regulation of asylums and most contained provisions that endeavoured to protect inmates from abuse and neglect. They were unsuccessful in this regard. People are protected by legislation only in so far as the system for its enforcement is committed to its fundamental intent, and is able to follow through. Many variables act against such legislation having more than a token impact on people's lives. In Australia, the depression of the 1890's devastated the colonial economies. Its effects aggravated the impact of lack of

political will, eugenic theory, overcrowding of existing facilities, and reliance on a system of care – institutionalisation – that could never be safe. People could not be protected by legislation that was unenforceable.

The New Norfolk Asylum made some separate provision for mental defectives as early as 1862, locating several in a cottage adjacent to the Asylum. But no attempt was apparently made to offer any education or training. This type of initiative was left to Kew Cottages in Melbourne, which opened in 1887. The establishment of the Cottages followed a Government Committee of Enquiry headed by Euphrain Zox. The Zox Report included a recommendation to establish a small institution based on the cottage model for feeble-minded children as an alternative to incarceration in a large institution for lunatics. A small private residential school for idiot children had operated in Moonee Ponds under a Dr Fishbourne since 1881, but Kew Cottages was the first opportunity to adopt a large scale curative and educative program geared exclusively to idiots and imbeciles anywhere in Australia. Sixty children were placed in three cottages that initially comprised the complex. It was an exciting time reminiscent of the 1850's in Massachusetts.

The period of excitement was short lived. In 1905, the Inspector-General of Asylums visited and reported:

Some of the inmates were difficult to handle and not many were able to face any attempts at formal education. The staff became mostly concerned to keep control, and a variety of methods were employed. Some were questionable and some, even for those days, were to be condemned:

- 1) The castration of epileptics.
- 2) The use of the revolving bed.
- 3) The use of the mouth gag: the child's mouth would be stuffed with rag to prevent him crying, complaining or making unacceptable noises.
- 4) The use of the straightjacket (invented by Quiller in 1790, and only abandoned in the Cottages in comparatively recent days).
- 5) The use of Rush's Compulsion Chair, in which the inmate would be enshrouded and left for periods as long as a couple of months.
- 6) The application of the Cold Water Cure. The contents of several hundred buckets of cold water would be tipped over the inmate.
- 7) The application of the Upright Posture Theory. Charles Darwin had postulated that the strength of one's upright posture varied in direct proportion to the level of one's intelligence. Hence Dr E. Horn speculated that the inmate should undergo a tortuous trick in order to strengthen his back. He was to be rendered ineffective by being suspended from the rafters of the ceiling with his arms stretched out towards the walls of his narrow cell. Half a day of this would make him weary, sleepy and most of all docile. The pain caused by this indelicate operation was so severe that the mere hint of its repetition would quieten the most difficult of children.

(Lloyd 1987, pp. 6–8).

Any semblance of Kew Cottages being an educational facility ended in 1907 with an outbreak of typhoid and scarlet fever. The school was closed and became an isolation ward. Conditions worsened. In the early days, outings to the beach, concerts and other entertainment were enjoyed

by staff and inmates. By the time of the First World War, there were staff shortages, decaying buildings, apathy and deaths. Many were caused by influenza and measles, but others could not be explained.

The history of Kew Cottages is not at all unique. The same sorry spectacle of human neglect was played out throughout Australia in the first half of the Twentieth Century. Children with mild intellectual disability frequently remained at home with struggling families. As adults they often continued to be dealt with by the judicial system, regardless of whether they had committed any crime. Those with more significant disabilities usually found their way to the institutions established grudgingly by governments which self applauded their humanitarianism and remained blind to the truth: that people with disability were dying or living in endless suffering in Australia's institutions years after the genocide of their peers in Germany had been halted.

One cannot accuse Australia in quite the same breath as Germany, but death and suffering is death and suffering. There is no distinction in outcome between the death of a man with Down Syndrome through neglect at Kew Cottages, and the death of a woman with cerebral palsy through mercy killing at Hadamar. They both died. Both Governments and both societies were culpable. Institutions everywhere in Australia caused untold human suffering. A Royal Commission in 1905 investigated New Norfolk Hospital. Sixty-four of the 466 inmates experienced 163,222 hours of restraint in a one-year period. Malaria therapy, shock therapy, and leucotomies became common in the 1930's and 40's. Another Royal Commission, this time examining the Goodna (previously Woogaroo) Asylum in Queensland, considered bathing facilities Dickensian, sanitation appalling and rat infestations intolerable. Virtually all institutions had their bad publicity; all were identified as inadequate; all kept operating in much the same fashion after the hue and cry arising from their criticism died down.

In 1912, Doctor Richard Arthur, a Liberal Member of the New South Wales Parliament later to become Minister for Public Health, established the Eugenics Society of New South Wales. Legislation to segregate mental defectives was passed in South Australia in 1913 and in Tasmania in 1920. In 1924, Doctor M. H. Downey, Director of South Australia's psychiatric services and senior lecturer in psychological medicine at Adelaide University, observed:

... In the ultimate interests of the race ... the unfit (should) be left to the fate which would overtake them as a result of the free operation of Nature's law of the survival of the fittest. (Downey 1924, cited in Lewis 1988, p. 129)

The New South Wales and Victorian Parliaments debated Sterilisation Bills in 1930 and 1939 respectively. Perhaps those deliberating had a premonition of where they might lead. They never became law. But the underlying attitudes remained. There were still eugenics societies functioning in several states in the 1960's, and letters appeared in the *Medical Journal of Australia* concerning sterilisation for eugenics purposes as late as 1969.

As in North America and Europe, the middle of the Twentieth Century brought a whiff of change into the Australian context. Compassion and charity began to intervene more in the lives of people with disability. Some people with physical and sensory impairments were already served, at least to some extent, by organisations such as the Yooralla Society in Victoria and the Spastic Centre in New South Wales. Physical handicap was one thing; mental deficiency quite another. People were used to seeing men blinded and maimed by war, and polio outbreaks made physical impairment appear more common and somehow almost acceptable.

But neither children nor adults with intellectual disability aroused much philanthropic interest until after the Second World War. By then, new services and organisations were being established in most states as alternatives to large institutions. Frequently parent based, they started in local halls and disused buildings with names such as the Psycho-Care Society (later to become the Subnormal Children's Welfare Associations of New South Wales and Queensland), the Retarded Children's Welfare Association of Tasmania, and the Slow Learning Children's Group of Western Australia. These organisations still exist, if with different titles and management structures, and remain a powerful force within the Disability Industry. They swelled the ranks of the few pre-existing non-government institutions such as the Sunshine Institute in Sydney and Minda Homes in South Australia. Together, they began to have an impact on the way people with intellectual disability were perceived and the manner in which services were delivered.

The early history of the parent-driven organisations in Australia is a moving account of services built on despair. Parents in the 1950's and 1960's had two alternatives: cope at home or place their child in an institution. The contrast was stark, and often neither option was at all desirable. A description of Claremont Mental Hospital in Western Australia was typical of such facilities across the country:

The care was appalling. In the male children's ward, J Block, there were people who lay in bed with bed sores until they died ... Many who were incontinent were often hosed down outside, even in winter in the so-called airing court. There was no individual care, there was no love, there was no care at all and all bad behaviour was coped with in the medical fashion, using what some used to call 'chemical warfare' against them. (Cited in Cocks et al 1966, p. 78).

On the other hand, at home the Australian dream could become a nightmare. Life in the new brick house on the quarter acre block with the Hills hoist and the Holden car did not function as the Women's Weekly said it should. For Gwen Anderson, who already had two children and a husband working full time, a young child with microcephaly was almost too much. With his wife on the verge of a nervous breakdown, Frank Anderson approached the Daily News newspaper in Perth. Following sympathetic publicity and a series of public meetings, the Mentally Incurable Children's Association was established. Politicians were lobbied and a property was acquired for use as a hostel. Fundraising barbeques, jumble sales, street appeals, lamington drives and concerts raised money for furniture and operating costs and so the fledgling organisation grew and developed.

The pattern was the same in every State. In desperation, parents banded together, pressured governments, raised funds, gained a measure of public support, and worked and worried to establish and keep under-resourced and over-taxed residential and other services operating. Facilities were opened with great pride and acknowledgement of untiring efforts by parents and others involved. It is impossible to fully appreciate today the voluntary time and effort contributed, and the impact this would have on the Disability Industry.

Governments took more notice. The economic boom after the Second World War enabled more generous funding of social programs generally, and the entire country entered an expansive, if paternalistic, caring phase in its treatment of disadvantaged groups. As indigenous people and others benefited, and suffered, under this new focus of attention from the State, so too did people with disability. Small, purpose built hostels, sheltered workshops and special schools were followed by the first early intervention programs, activity therapy centres and community

support services. The changes seemed gradual but, in the context of history, were rapid. National organisations such as the Australian Council for Rehabilitation of the Disabled (ACROD) and the Australian Association on Mental Retardation (AAMR) became powerful lobby groups. Professionals from a variety of disciplines banded together in groups such as the Australian Group for the Scientific Study of Mental Deficiency (AGSSOMD). The power and influence of the doctors over those with intellectual disability decreased with the medicine of the mind – psychology – taking centre stage.

Thus, by the 1970's, a quite sophisticated system had developed for the delivery of professionalised human services. Doctors diagnosed conditions and recommended parents deliver their children into the lifelong care of local charities or, if desperate, the less local and less desirable but still available government institution. If the child was fortunate, it might receive specialised education with other handicapped children in the segregated but safe environment of a special school and go on to work, or be (un)occupied forever in an activity centre or sheltered workshop. Home would be shared with between twenty and a hundred others in a large, initially well-appointed hostel with, for the most part, staff projecting a kind of benevolent but distant authority. Life was deemed good by those who felt they knew best – the parent-based, non government charity service providers – who had worked tirelessly in the face of professional, public and government apathy to see their dreams (as distinct from those of their charges) reach fruition.

Those less fortunate might live with a thousand others in a state government managed complex of buildings, up to a hundred years old, with decaying infrastructure but an army of tradesmen repairing plumbing, installing temporary accommodation, painting and patching in an endless cycle of desultory activity. During the day, patients in the process of being re-named residents (or in the most advanced, groundbreaking facilities, clients), might spend a few hours learning skills of daily living, unlikely ever to be practised in the real world, under the direction of a Program Officer or other staff. The remainder of their day would be largely aimless, with mealtimes, bath time and bedtime the key periods of activity and stimulation. Life was not so good and often involved danger and fear, and rarely any love or more than fleeting affection.

By the 1980's, the Disability Industry was omnipotent. There were internal divisions between conservative and progressive elements that created dissent and debate from time to time. There were those who were pro-institutions still, and those who were vehemently opposed and promoted the group home as an alternative service model. There were others who favoured organised charity while their opponents clamoured for equal rights, not charity. Still others were rabidly pro-SRV theory with their critics accusing them of being Normalisation brainwashed zealots. But overall, the Industry was one entity and was all powerful. And within the Industry the professional expert was all powerful.

Yet, as we have seen, history declares there is questionable wisdom in placing too much faith in the allegedly science-based judgements of experts. Notwithstanding good intentions, professionals are neither inclined nor well placed to get to know personally, and stand in kinship with, individuals who have disabilities. There is little evidence that there was any more recognition late in the last century of the need to be kind, caring, helpful, friendly, tolerant, respectful, and personally connected to people with disability above all else, and to helping people toward living an ordinary life, than there was a hundred years before. Conditions were immeasurably improved, but one cannot help feel that people with disability were and still are perceived as

different, as somehow a sub-species of the human race, with all the negative consequences of that benevolent, professionally determined distinction evident in their daily life.

These are immensely important lessons to be learned from the history of the Disability Industry. The assumption that prevailing professional attitudes, and the best of our contemporary services, constitute the right way to be doing things is wrong. For example, the observations of Doctor Downey in 1924 were based on erroneous opinion. Time is likely to prove the professionally conceived notion of providing services to consumers equally flawed.

While the language may have altered, the parallels between the past and present are many. Where inmates were once institutionalised, clients are now serviced – the same principle of overtly and constantly distinguishing between the ‘capable’ and the ‘incapable’ remains. People are still diagnosed and then served according to their impairments; their personal gifts, characteristics and preferences are secondary in determining how they live their lives. Professional expertise remains sanctified; personal charity and helpfulness is viewed as patronising and is often demonised by the politically correct professional elite. Vast resources are expended on the infrastructure of the Disability Industry at the expense of the people it purports to serve. Theory replaces theory, therapy replaces therapy, new ‘models’ of service delivery replace older models of service delivery. Treatment is different but the pattern remains the same. Perception of ‘the disabled’ remains firmly mired in an exclusionary paradigm. John Smith is not the fellow next door; he is one of the retarded clients in the Group House for the handicapped.

Human service organisations have, in the last decades of the Twentieth Century, done much to alleviate obvious suffering. The majority provide services that have removed or kept people out of institutions. They have provided respite to families and they have lobbied, often successfully, for increased recognition and resources from governments and the community. They have been responsible for genuine improvements in the quality of specific aspects of many people’s lives.

They have also, however, been responsible for continuing and even increasing the rate at which human service (ie. personal caring) is displaced by formalised human service structures. They have also labelled and stigmatised people with disability as clients and consumers, and thus emphasised any pre-existing perceived and real difference from the rest of the community. They have created more and more policies and procedures, techniques and technologies, and fads and fashions that employ more and more human service workers in often irrelevant and sometimes harmful tasks. And they have trained essentially good, caring, ordinary people to become professional providers of services. Many become ensnared in the policies and politics of the Disability Industry and their careers and, as a consequence, lack time or awareness to remain just good, caring human beings.

The future for people who have a disability is probably more of the same, with an inevitable evolutionary refinement of human service systems. With a little more thought things might be different – at least for some people. Some human services should desirably have a limited future. Staff and others involved with such organisations should, where possible, be endeavouring to support people in real relationships and contacts with their natural community. For the foreseeable future most specialist organisations serving people with disability will continue to function with their professional service delivery culture largely unchanged. Until there is some assurance that the people who are supported through them might be better assisted outside their structure, they presumably must remain.

The example of the L'Arche communities and other person-oriented support arrangements indicate however, that formalised service systems are only necessary because people believe they are. People with disability do not require formalised human service structures in order to live an ordinary, supported life in the real community. It is simply that the history of humankind has structured the contemporary worldview that way. John Smith does not need to live in a special purpose Group House with highly trained professional Residential Care Officers implementing his Individual Program Plan. He does so only because it is Disability Industry doctrine. But such doctrine is verisimilitude. It has the appearance of truth and reality and necessity but it is no more immutable than was the 'science' of the eugenicists. Eugenics was merely an attitude, a state of mind, as is the Disability Industry dogma that says people must be serviced and therefore viewed and treated as consumers or clients.

Instead, individuals seeking to pursue a moral approach in contemporary terms must develop ways of being true to the ideal of helping people with disability to lead ordinary lives, rather than lives tainted by clienthood. There is no doubt that today's Disability Industry is a modernised clone of that of a century ago in many respects. There are specialised residential and other services varying markedly in quality. Professional experts, with earnest endeavour, produce a variety of treatments, therapies and programs, overconfident of their diagnosis and their techniques and oblivious to the negative consequences. Solutions to 'problems' are sought at the expense of caring. Abuse continues, though it is mostly insidious rather than overt. Industry practice exacerbates the distinction between people with disability and those without, despite good intentions. Bureaucracy and formalism stifle personal commitment and effort. And there is always a lack of resources made infinitely worse by the mis-application of those that are available.

Conversely, the approaches that succeeded a century ago still work when practised today. Personal caring, genuinely individualised assistance, support networks in the community, and small informal organisations that pursue a 'moral' approach can succeed in assisting people with disability to achieve a (close to) ordinary life, where an industrialised and commercialised welfare service culture does not and cannot. The challenge is to harness the good intentions of those who seek the best for people with disability to these time honoured good practices. In the process, belief in the corporatised approach of 'servicing clients' needs to be carefully abandoned. No Industry can ever manufacture caring. And the history of the Disability Industry is clear proof.

* * * * *

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An Autistic Child to His Mother

My window to the world is
A fractured globe of glass turned
In upon itself –
Through it I can sense other worlds
Which sometimes thrill or threaten me,
But I have no words to share with you
Just what it is I sense,
Or what it is that threatens me.

But look into the mirror of my eyes to see yourself;
To see, perhaps, how I might perceive
Wind-storms tossing trees against the blue of shredded sky;
To hear with me the creaming of the waves on
Shingled, pearled beaches,
Or smashing, gleaming foam high upon the torn and ragged
Cliffs,
Or secrets chattered by the creek to pebbles on its sandy bed –
A bird's song,
The flash of butterfly, the hum of bees and
Scent of roses.

If you hold me tightly, I shall struggle to be free –
I need to fly from deep within myself
Like Icarus, to reach the sun and warm myself to
Love and life and laughter,
But cannot.....

For I have no real sense of who I am – to me or you –
And can only mutely beg your love be always poured on me from
The well-spring of our grieving --
For we still are one.

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K. Thomas (Caitlin Louise Thomas)
10.07.2004

**Lost child....
How silently
Your steps...your shadows glide
Across that wide pond...rippling
My grief.**

Bruce

I was born in July, 1965. In October that year, the family moved to Nowra on the south coast. At Easter, the following year, I came down with bronchitis and was sick with it until just before my first birthday. At the time, if you were a patient of one G.P., another doctor would not see you. The doctor I was seeing had come from New Zealand and my parents did not know a great deal about him, as it was, he treated the bronchitis with repeated doses of streptomycin. It was found out later that the bug was responsive to penicillin. I became much worse and developed a very high-pitched scream. The doctor bundled me up to the children's hospital at Camperdown (Wade House) to see a friend of his – a paediatrician. My parents trusted them both, but this trust was misplaced.

I was dumped in a cot and my mother wanted to stay with me but was not allowed. Only after did she find out that there was accommodation for country mothers at the hospital. I remember seeing her leaving me, crying. I felt they had dumped me and I did not know why. My parents came back after a few days on the weekend. They were told that, by the time I had been put into hospital, the bug had gone. I was just starting to talk when I got sick, but now I couldn't do anything but sit and twirl things around. I remember standing holding onto the side of the cot and seeing my mother leaving, crying after this visit too. I thought she did not want me, so I just sat down in my cot and kept twirling a little toy someone had given me.

A few days later, my parents came to take me home. My mother had looked at the charts at the bottom of my cot and there was nothing there but the temperature charts. Years later, Professor Beveridge at the Children's Hospital at Randwick got the notes from Wade House and told my parents there was nothing on them but these temperature charts, and he could not make a prognosis. My mother still thinks that the doctor at Wade House thought I was going to die and did not bother about me, and that he was covering the negligence of the doctor at Nowra who could have done a lumbar puncture at the local hospital and prescribed the right antibiotic.

All I could do when I got home was to sit up and play with the same thing, a top, over and over again. When my parents, brother or sister spoke to me, I did not respond because I could not talk. When I could walk – about two years of age -- I found I could climb the front fence and get out. I did this quite often and found my way to the house of another little boy who had a similar problem. We liked to play together.

I did go to the local kindergarten when I was two and I was smacked for playing their piano -- a big black piano. I could not understand this, because Mum used to sit me on her knee and play our piano with me back at our house. We both love music. I became frightened of

pianos and would not go near them, and I was frightened when anyone else tried to play any piano, particularly at home. This was very hard on my sister who would have loved to have learned to play it.

By this time, my baby brother had arrived. My mother was very sick and was in hospital for a lot of the time towards the end and was very weak when she finally did come home. It took her a long time to recover from the Caesarian operation. I felt more left out than ever. I was very angry, too. I could not talk and let anyone know how I felt, and my baby brother was taking up most of my mother's time. My elder brother often used to try and play with me and look after me, and my sister helped my mother with the new baby after school.

My mother used to drive up to Wollongong public hospital every fortnight to a speech therapist who, after a few months, decided it was a waste of her time, as I could not talk! My mother was very angry and upset – and so was I, but I could not speak and did not know how to say so.

When I was three, there were frequent visits to Sydney to various specialists to try and find out why I could not talk. Finally, I was taken to a doctor in the Public Health Department who said I was autistic. My mother tried to argue with her that I had been talking before I became ill, but she was very arrogant and rude, demanding to know what my mother would know about it – *she, i.e. the doctor*, was the “expert”.

The School for Autistic Children had just opened at Belrose and my parents were told I should go there.

This meant re-locating the whole family to Sydney. At first, my mother and I stayed in a unit at Manly Vale and we used to travel in to where my mother was working with the Education Department and a taxi picked me up from there to go to school. The rest of the family were in Nowra, being looked after by a wonderful lady who came in each day. On Friday night, my mother and I would catch the silver train back to Nowra to be with the others, and go back to Sydney on Sunday night. This went on for about six months until my father could get another job in Sydney when the whole family was uprooted and my brother and sister had to start new schools. Because my mother still had to work, my baby brother had to go to a pre-school kindergarten from the time when he was quite small.

I wasn't the only one affected. When we came back to Sydney, my big brother went to Seaforth Primary School in sixth class and the Principal told my mother he'd put him in “D” class (classes were streamed then) and if he had had an “F” class, he would have put him in that! My brother went on to go to University, do Honours and is now an archaeological consultant in Melbourne.

The Principal of the primary school my sister went to refused to let her repeat sixth class and my mother was told he only repeated those who were bright enough to benefit from repeating, so she was sent to high school at Mackellar Girls' High and was put in a class with all the troublemakers. This did quite a lot of damage to her. But, in spite of this, she went on and did a brilliant degree in visual arts. Because I could not talk, the schools assumed there was something wrong with my brother and sister!

My younger brother was similarly discriminated against all through his school life, even when my mother mistakenly sent him to a private school in the Blue Mountains where we lived

– he was particularly discriminated against by a good “Christian” family in the area.

When my mother was working with the Department of Education, she had contact with counsellors in the Department who specialised in work with children with special needs. They told her that I was an “expressive dysphasic” which is not the same as autism, although dysphasia can be part of autism. They tried hard to get me into a special class, but were overruled by the Department. Consequently, the medical diagnosis overrode the educational.

As a result, I went from the school at Belrose to a special education class at Hornsby, and have been farmed out to various government departments and their miserable provision for the intellectually disabled; so, over the years, I have become progressively regressed educationally and socially. Part of this treatment has been their over-medicating me with psychotropic drugs so that I conform to the status quo.

Later, I did spend some time at the Rudolph Steiner school at Dural because, I have to admit, I was hard to live with. I was hyperactive and did not sleep much which meant my parents did not sleep much either. I often used to end up in bed with them because I felt so frightened and insecure. The Steiner School was a miserable experience after a time and, when I hit someone who was teasing me because I could not talk, my father had to come from his work and get me.

Sometimes I got out of the house and was brought back by the Police. One afternoon, I got down to Manly Wharf and went over in the hydrofoil to go to the station and catch the silver train back to Nowra, but the gatekeeper at Sydney hospital caught up with me and called the Police. When Dad got home from work, the family drove into town and picked me up from the Phillip Street Police Station. My younger brother burst into tears when I told him they had given me ice cream, cake and a cup of tea. (They hadn't really – I was just teasing him.)

When Andy started school, he learned some swear words in Italian. I was beginning to talk a little bit then, and Andy taught me these new words. We didn't know Mum was listening behind the door. After a while, she stopped him and said,

“Now Andy, if Bruce were a little blind boy, you wouldn't take him to the edge of a big hole and tell him to keep walking, would you?”

Andy was shocked at the thought – “Oh, no Mummy, I would *never* do that!”

So Mum explained that I didn't know what the words meant, and if I used those rude words I might get myself into trouble. Andy was contrite, but I thought it was a great joke because Andy didn't know what they meant either!

My mother took me to a reading specialist who assured her that I could be taught to read, and was given a program and began teaching me (by this time she was a qualified teacher). But, between my father and the government department which was supposedly looking after me, this was stopped. It is very simple – one copies what one sees. Bandura states “children learn what they see”, so obviously when I was cooped up with people who were worse off than I, I sank down to their level simply to co-exist – I couldn't say I was living.

One of the group homes I spent time in was run by a psychiatric nurse from Stockton Hospital. She was a nasty piece of work. She made us stay in the house after tea at night and watch television. We were souped to the eyeballs with medication, and had to go to bed right on 12 o'clock – no earlier, no later.

We were regimented from the time we got up in the morning until we went to bed at night and there was nothing much for us to do during the day.

I was always getting into trouble because I didn't want to watch T.V. because, after all, I couldn't understand much of what was said. I had a real blow up one night and smashed some furniture and a couple of windows. The Police were called in and I was arrested and sent to the Lachlan Centre. The Director of Nursing at the Centre was the *fiancé* of the house manager. (This Centre became the subject of intensive investigation after the Burdekin Report, but nothing much has changed.) I was terrified, I did not know what was happening to me and, again, I couldn't explain how I felt about the house and the manager. My father had to leave work and take me home. I went to a workshop at Bantry Bay for a while and lived at home with Dad. This was good for a while, but one of the fellows there teased me because I couldn't talk and I hit him and that was the end of that. This has happened a couple of times, and people who run workshops and homes for people like me don't seem to know what a heartache it is to have too much you want to say and do and not have the language to express it.

The only thing left to me now is my drawing and woodworking. My mother had a psychologist test me and the results showed that the visual-spatial part of my brain was intact and there appeared to be damage in the Broca's area of the brain which causes me not to be able to respond in a conversation. This causes a great deal of misunderstanding and frustration and there are very few people who really get the picture. They still expect me to be able to be like them. Actually, I am a lot brighter than many of them, but I have been labelled as having a "moderate intellectual disability".

That is the box the medical and associated professionals have put me into and that is where I must stay because society does not care, and often carers do not understand how desolate I feel.

I have had years of mistreatment and misunderstanding through organisations such as ad hoc DoCS and the Department of Health facilities and, when I can't make people understand, I sometimes get very frustrated and angry. People who can only think of this behaviour in relation to themselves call this "challenging behaviour". What their ignorance prevents them from seeing is that their ignorance is continually challenging and frustrating me. I have a disability, i.e., I cannot talk the way they can. I am not stupid.

When I was about 30 years old, after being hassled by government group homes and respite houses, I began to stutter badly and have never been able to get over this. It is a real struggle to get anything out and I really get upset if my routine changes, because I have been so disempowered by those who think they know what I should want and need, I cannot tell them what I feel I need or want. I have given up! I'm nothing much more than a robot now.

As well as this, I have recently been diagnosed with a heart murmur thought to have been the result of the illness I had as a baby and have developed Type 2 diabetes. Both my parents are diabetics and the years of stress I have suffered through the ignorance of my so-called "carers" has affected me also.

Apart from my being arrested by Police, the next worst incident was when Mum and I went to Jenolan Caves for a picnic. I was in a respite home at the time at North Ryde, where one of the staff was a great pig of a man who liked to let me know who was "boss". It is no surprise that so many staff who "care" for people with a disability are people who feel inadequate in

themselves and need to bully people who are more disadvantaged than themselves to bolster their self-esteem.

We got out of Mum's car at the Caves, and who should be waiting for us but "Bully Beef" and his family. He knew we would be there, because back at the house what every person was doing was written down in a log.

He swanked up to my mother and introduced himself and his family and told her that if I gave her any trouble to get him. Mum was furious. We moved right away from him and got our tickets for the cave. While we were waiting, the pig came up and waited with us. This was harassment of the worst order. He had deliberately waited to see which cave we were going into then bought tickets for the same tour. I often wonder what he may have told the guide.

However, Mum was awake up to him. In the cave, we stood aside until everyone else had gone past before we joined the queue. The paths are very narrow, so he couldn't turn back and come after us. Mum had a word to the guide, and he stayed between us and the other people to prevent an incident. The "bully" looked pretty angry when he came out. We just walked straight past him as though he weren't there.

Mum did write to the area office and complain, and received the same bored response we have grown used to from departments and others. Smug and secure in their positions with their pay rolling in each fortnight, they couldn't care less about the pain they cause. But if it had been an offence in a private body, there would have been hell to pay. They have their trade unions for protection. The disabled do not!

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CRIMINAL JUSTICE AND INDIGENOUS PEOPLE WITH COGNITIVE DISABILITY

Jim Simpson and Mindy Sotiri

This article is based on a project and discussion paper done by the authors for Aboriginal and Torres Strait Islander Services, Australian Government. The project included an Australian literature review and consultation with a wide range of individuals and agencies in the Indigenous, human services and justice sectors. The project had a national focus but a tight timeframe largely limited the consultation to New South Wales, Western Australian and the Northern Territory.

Introduction

This article is focused on issues for Indigenous people with cognitive disability who are in contact with the criminal and juvenile justice system. The focus is on issues for alleged offenders, victims and witnesses with cognitive disabilities. Cognitive disabilities include intellectual disability and brain injury flowing from trauma or substance misuse.

The diversity of Indigenous communities throughout Australia means that generalising about the needs of people with disability within these communities is very difficult. There is, however, an unfortunate consistency across Australia with regard to the high levels of social and economic disadvantage experienced by Indigenous people. Any discussion of cognitive disability in Indigenous communities needs to be placed within the context of this disadvantage. Being both Indigenous and having a cognitive disability is potentially a major dual disadvantage.

Prevalence and recognition

The available evidence suggests that Indigenous people with cognitive disability are highly represented as offenders and victims in the criminal and juvenile justice systems.

Cognitive disability is frequently not recognised by justice system personnel. Recognition is even less likely if the person is Indigenous. There are a number of reasons for this interplay, including:

1. The different conception of disability in many Indigenous communities and the associated absence of recognition of disability. Indigenous communities tend to just accept the manifestations of a disability as part of a person's makeup rather than see it as a "deficit". There are obvious pluses to such acceptance but also a possibility that it leads to people not getting help that they need.
2. The mistrust many Indigenous people have of white organisations and the associated fear around disclosing disability.

3. The manner in which cognitive disability is masked as a consequence of other social and economic disadvantages as well as cultural factors. For example, English may not be a person's first language. Hearing impairments are common in Indigenous communities as is poor literacy and numeracy. The person may be influenced by alcohol.
4. A lack of appropriate consultation with Indigenous communities with regard to the 'needs' of Indigenous people when in contact with the criminal justice system.
5. The absence of services and culturally relevant assessment tools.
6. A lack of training, skills and time in criminal justice system settings.

Although many Indigenous people do not separate out cognitive disability from other social or health issues, this approach is complicated within the context of a western criminal justice system. The identification of a cognitive disability within these processes can have a very distinct impact on police practices, court proceedings and sentencing options. This impact is often, though not necessarily, beneficial to the person. For example, it can lead to the right to a support person in police interviews and can be an additional mitigating factor in sentencing.

However, the label of 'disability' also has the potential to further stigmatise an already marginalised population. The challenge for service providers becomes largely about how to ensure that Indigenous people with disability are treated fairly and have access to the same 'rights' as others throughout the system without exacerbating disadvantage by creating an additional 'stigma'.

Police

People with cognitive disability tend to be disadvantaged in police interviews as both offenders and victims. Alleged offenders are rarely aware of their rights in custody, whilst victims of crime are often not taken seriously, or prematurely judged with regard to their ability to make a reliable witness in court. Police interviews can yield very unreliable statements if the police are not skilled in communicating with a person with a cognitive disability or if the person lacks appropriate supports.

Aboriginality is another source of disadvantage. There is also a very problematic history to the relationship between Indigenous people and the police, and considerable distrust of the police in Indigenous communities.

Court

There are many characteristics of the court process which present significant difficulties for Indigenous people with cognitive disability:

- The formal and intimidating environment,
- The complexity and inaccessibility of legal language,
- The speed at which cases are heard and the absence of time with legal representatives,
- The often lengthy period of time between being charged with an offence and the court hearing,
- The absence of Indigenous support workers, and
- The need for training about disabilities for all court staff including judges and magistrates.

Formal court processes often do not adequately meet the needs of Indigenous people or

people with cognitive disability. Where alternatives to mainstream courts exist, these should be utilised. Court processes also need to be improved.

Prison

Imprisonment can have various negative effects on all prisoners but especially those with other sources of disadvantage, such as Aboriginality and disability. These negative effects include reduction of living skills and self-esteem, increased feeling of alienation and identification with an offending culture. Indigenous people with cognitive disability are at risk in prison both from other inmates and due to their not understanding prison rules and unwritten codes.

Because of the extent of over-representation of Indigenous people in prison, and the history of Indigenous deaths in custody, Aboriginal communities view imprisonment less in terms of punishment for the crime, than in terms of disadvantage.

Aboriginal specific programs have consistently been found by Aboriginal people in prison to be more meaningful than mainstream programs. There need to be culturally suitable programs which are pitched at a level which is appropriate to the cognitive ability of the participant.

Specialist disability units exist in some jurisdictions for those who are not able to be placed in the mainstream prison environment. The success of these units depends on appropriate levels of funding and program staffing. These units may provide the best option for some Indigenous prisoners.

As part of minimising the negative effects of imprisonment, maintaining links with a prisoner's community is very important, links to both family and Indigenous service providers.

Indigenous offenders with cognitive disability have an obvious need for support when they leave prison. However, there are very few post-release services in Australia which are suitable or accessible for this group.

Diversion, Alternatives and Sentencing Options

Diversionary programs and alternative sentencing options occur at different stages in the mainstream criminal justice process, and require further investigation with regard to their accessibility for Indigenous people with cognitive disability. There are various mainstream programs, and some particularly for people with disability and some particularly for Indigenous people. At this stage, there are none specifically focused on Indigenous people with cognitive disability.

Significant programs identified in this project include:

- The (intellectual) Disability Diversionary Court in Western Australia
- Youth Justice Conferencing in New South Wales.
- The Koori court in Victoria which involves elders, family members and Aboriginal justice workers in the sentencing process.
- The Port Adelaide Nunga Court which has an Aboriginal elder sitting on the bench with the magistrate.
- Circle sentencing which has been piloted in NSW and involves the offender, the victim and the local Indigenous community in the sentencing process.
- Programs for people with drug problems, including the Drug Courts in NSW and the Northern Territory, and the Magistrates Early Referral into Treatment Program in NSW.

- In NSW, magistrates have a discretion to dismiss a charge against a person with a developmental disability or psychiatric disorder, including with conditions that the person cooperates with assessment or treatment.
- Mainstream alternatives to custody such as home-detention, community service orders and periodic detention.

Alternatives and diversionary programs are often deemed not suitable for particular groups with potentially high needs. This is usually framed with regard to the inability of the person with the high needs to properly understand or comply with the process. However, this view may be masking the need for the program to be more flexible and offer people with cognitive disability a greater level of support.

Human Service Needs

Legal protections are of very limited use to Indigenous offenders with cognitive disability unless there are also culturally appropriate and accessible support services. The ability to lead a 'lawful' life is complicated by a range of factors, including socioeconomic disadvantage, a feeling of alienation from white society and the discriminatory effect of laws. If community supports are not available, and the range of factors which impact on offending behaviour are not being addressed, there is a likelihood that dismissal of charges, bonds or release from prison will just be followed by further offending and trouble with the law.

The project's consultation confirmed that these support needs are commonly not met. Even the most basic needs of Indigenous people with cognitive disability are frequently not met. People are homeless and have poor access to health care. In addition, many services are not accessible to Indigenous people. Many Indigenous people feel very uncomfortable using mainstream services.

There is a paucity of human services for offenders with cognitive disability, whether Indigenous or non-Indigenous. The needs of this group vary but range across – support coordination/ case management, clinical intervention directed at the offending behaviour, education and training, accommodation and related support, alcohol and other drugs services, mental health services and flexible approaches to promote acceptance of services. There needs to be a flexible and coordinated response from mainstream agencies, specialist disability services and Indigenous services.

Actions by human services need to recognise the following factors:

- So far as possible, assistance should be based on need rather than defining a person as having a disability.
- The diversity of Indigenous communities and of individual Indigenous people.
- The importance of maximising the links between Indigenous offenders and their communities, cultures and heritage.
- The deep socioeconomic disadvantage in Indigenous communities.
- The importance of well planned communication and coordination between the range of people and agencies involved in assisting a person.

Demarcation issues are a major problem. For example, adults with acquired brain injuries often fall between disability and health services.

Victims of crime often need support services such as counselling. It is very important that

these services are culturally appropriate and suitable for people with cognitive disability.

Issues for Action

The central requirement is for the systemic socioeconomic disadvantage facing Indigenous Australians to be remedied. However, more specific action is also needed to respond to the needs of Indigenous offenders with cognitive disability. Some of the main issues needing consideration are:

1. Discussion with Indigenous communities about the impact of cognitive disability and how to better meet the needs of people with cognitive disability in the community and in the justice system
2. Training of justice system personnel in culturally sensitive recognition of, and appropriate response to, cognitive disability including through having relationships of trust with Indigenous communities. This applies to police, lawyers, the judiciary and correctional agencies.
3. Enhanced access to interpreters in Indigenous languages.
4. Further development of culturally valid and acceptable methods of assessment of cognitive disability.
5. Development of rights based support networks for Indigenous people with cognitive disability in police interviews and in court.
6. Resourcing family support and visitor schemes, to ensure family and other visitors for Indigenous prisoners with cognitive disability.
7. Ensuring access to Aboriginal medical and legal services and other Indigenous service providers for Indigenous prisoners with cognitive disability.
8. Development of mainstream and Indigenous specific diversion and alternative programs that are suited to Indigenous people with cognitive disability.
9. Enhancement of the capacity of Indigenous communities to provide support to community members who have cognitive disabilities, both through natural support systems and through funded programs, for example mentoring programs and skills development programs.
10. Enhancement of the capacity of service agencies dealing with Indigenous offenders to identify and respond to cognitive disability and in a culturally respectful manner.
11. Government service agencies remedying practices and service gaps that restrict their capacity to assist Indigenous people with disability such as:
 - Demarcation issues in relation to people with adult acquired brain injuries and those with dual disabilities.
 - Gaps in service provision eligibility between minimum school leaving age and adulthood.
 - Restrictions on which service providers can be funded for particular purposes.
 - Restrictions on employing relatives as carers.

The authors of this article and the discussion paper on which it is based are not Indigenous. They did receive a lot of very valuable input from Indigenous people which heavily influenced the paper. The authors' hope is that the paper provides a basis for discussion in and with Indigenous communities. It is very important for Indigenous people to be central players in carrying forward issues raised in the paper.

BOOK REVIEWS

Challenging behaviour and developmental disability

Sigafoos, J., Arthur, M., & O'Reilly, M. (2003)

London & Philadelphia: Whurr Publishers. ix,161

There is possibly no other issue in the field of developmental disability that has received as much attention, from both research and service delivery perspectives, as the challenging behaviour of people with disability. In large measure, it was this specific behaviour that led to a demand by family members for support; support that was provided in earlier times in institutional settings. A large proportion of people with a developmental disability, living in special community accommodation such as group homes, has been supported in those settings because of behaviours that make living in their natural homes problematical.

It is in this context that Sigafoos, Arthur and O'Reilly address the serious service delivery and policy implications of so called "challenging behaviours". One is immediately impressed by the authors' determination to address what is and what is not a challenging behaviour. Equally refreshing is their attempt to portray a socially and empirically valid conceptualization of challenging behaviour. For instance, they state that:

It is important to have some sort of framework – theory if you will – of challenging behaviour that integrates what is known about behaviour and human nature in general and one that can account for why and how certain factors increase the risk of challenging behaviours in people with developmental disabilities. (px)

It is this conceptual base that is put forward in the first of the four parts of the book. Other sections outline fundamental issues in service provision, assessment and finally treatment and prevention.

I found that the strength of this relatively short book was its attempt to provide the reader with an evidence-based understanding of the nature of challenging behaviour and the basic scientific principles that form the basis of assessment and intervention procedures.

It is definitely not a 'cook-book' with simplistic recipes to follow. Nor does it promise that one specific approach will succeed. What it does, however, is to provide the reader with a set of principles that will help in a clear understanding of the purpose of the challenging behaviours.

I also believe that the authors have achieved their goal of placing the issues in the framework of basic human behaviour. We often forget that the person exhibiting the behaviours is first and foremost a human being with the same needs as everyone else. The authors comment, that "to understand challenging behaviours in people with a developmental disability is to understand human nature", is indeed prophetic.

The evidence drawn upon has been carefully selected from leading researchers in Australia, the U.K. and the U.S.A. and is highly relevant to the Australian scene.

It is a book I strongly recommend to a wide variety of professionals working in the field of intellectual disability and other developmental disabilities. The reader would need to have

had some prior practical exposure to challenging behaviours in order to understand better the material being presented.

The text style is highly readable, not didactic nor patronising. The authors, who are leaders in the field, lead the reader through a range of theoretical and practical issues that will have a lasting impact upon professional practice.

I rate it as one of the best books on this topic to emerge in recent years, especially as it links research to practice. Its strength undoubtedly lies in the authors' clear articulation of a framework that helps us to understand and analyse the often contradictory and sometimes strident claims of the "snake-oil salesmen" who promise quick solutions to seemingly intractable problems.

Trevor R. Parmenter. PhD

Working Relationships: Creating Career Opportunities for Job Seekers with Disabilities through Employer Partnerships

Luecking, Richard G., Fabian, Ellen S. and Tilson, George P.

Paul H Brookes Publishing Co., Post Office Box 10624 Baltimore MD 21285-0624

This book's stated goals are:

- To show that there is a job for everyone who wants to work, and
- To professionalise interactions between disability employment services and employers.

The text contains a wealth of useful ideas with some of the major themes including:

- The importance of knowing the job seeker and ensuring that job search is driven by each individual's uniqueness. The authors suggest going beyond each job seeker's stated job preference and exploring their interests and hobbies, as well as how work will fit within their life, to achieve an optimal job match.
- The importance of understanding the employer and ensuring that the job meets their needs including bottom-line considerations. The authors are respected practitioners and the book is endorsed in the foreword by the Chairman of Marriott Corporation: 'The experience of the Marriott companies is that the corporation's bottom line and the employment of individuals with disabilities are not incompatible. This book explains why.'
- How to develop employer partnerships that yield multiple placements. Successful partnerships are seen as based on mutual trust, mutual gain and long-term relationships. Case studies are included for the Marriott Corporation and the Cincinnati Children's Hospital.
- The importance of the agency's service quality and reputation. The suggestions for improving quality include using customer satisfaction surveys or focus groups to guide process improvement and guidelines for successful change management.

Finding the optimum job in open employment for a person with a disability is a challenge faced by every open employment service. Most open employment service staff come from welfare or education backgrounds and tend to focus on existing jobs and on the needs of the person with the disability without necessarily meeting the needs of employers. This text addresses both of these issues and I would recommend it as an excellent resource by respected practitioners that would be useful to any open employment service catering for people with disability.

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