

*i*nteraction

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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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Contributions (email attachment if possible to aiid@ncid.org.au) and correspondence to:
Australian Institute on Intellectual Disability
PO Box 771 Mawson ACT 2607
Ph (02) 6296 4400, Fax (02) 6296 4488
Internet Email: aiid@ncid.org.au **Home Page:** <http://www.ncid.org.au/aiid.htm>
Editorial Committee: Norma Rigby, Dulcie Stone, Monica Gourley and Mark Pattison
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i Editorial

While reading the draft discussion paper on the Productivity Commission's Review of National Competition Policy Reforms, I came upon this paragraph:

Funding systems and funding adequacy are also central to the quality of service and achievement of good outcomes. Inevitably, the provision of many human services will remain largely dependent on government provision or subsidy. **The scope to achieve better value for money in service delivery does not absolve governments from responsibility for providing sufficient funding to meet reasonable community needs.** It is incumbent on governments to specify what outcomes they are seeking from publicly funded human services and, after making appropriate allowance for expected improvements in delivery efficiency, identify what levels of funding are required to achieve those outcomes. As the Commission observed in its report on Nursing Home Subsidies, **without a clear linkage between desired outcomes and funding levels, there is the risk that service quality and/or accessibility becomes a 'residual balancing item'.**

Productivity Commission 2004, *Review of National Competition Policy Reforms*, Discussion Draft, Canberra, October; p 244.

The above emphasis is mine. My first thought was 'this is what families and people with disability have been saying for years – if the Productivity Commission can clearly see it, why can't politicians or bureaucrats'. My second thought was that they do but they just do not care, either about the quality of services or the need to "provide sufficient funding to meet reasonable community needs". Readers in NSW and South Australia will be well aware of community campaigns to ensure that their State Governments fully fund quality post school services for people with disability – campaigns which are only necessary because of the refusal of politicians and bureaucrats to listen to people with disability, families and the Productivity Commission.

To have the argument so clearly articulated by the Productivity Commission, and to know that politicians and bureaucrats have deliberately blocked their ears and their eyes, is very sobering.

While reading the paragraph from the Productivity Commission's discussion paper, several telephone conversations that I have had over the past months came to mind. I have received, unrelated, phone calls from four States from family members who have been denied supported living support, or who have inadequate support services. These families wanted information and advice on establishing self-contained supported accommodation. Essentially, they had given up hope and, to a degree, their dreams for their children, and were seeking ways in which they could provide accommodation for their children knowing that politicians and bureaucrats were never going to respond to their needs with adequate funding.

These are parents like hundreds and thousands of others. Families who have a desperate need for support, families who have made many applications, all of which have been turned down due to a lack of the ability and will of politicians and bureaucrats to provide adequate funding. Knowing that they will not get the assistance that they need and deserve, families are looking at ways in which they can provide the ongoing support that their daughters and sons need. They all said that the options they were considering were not what they wanted for their sons and daughters but they were better than living with the constant fear that they would die without any support being provided for their children.

We have returned to the 1950's, to an era where politicians and bureaucrats did not know how to respond to the support needs of families living with disability and so families established support services themselves.

But there is one important difference between the 1950's and 2004 – as the Productivity Commission clearly states:

It is incumbent on governments to specify what outcomes they are seeking from publicly funded human services and, after making appropriate allowance for expected improvements in delivery efficiency, **identify what levels of funding are required to achieve those outcomes.**

The Productivity Commission Report can be downloaded from: www.ncid.org.au/aiid.htm

Mark Pattison
Executive Officer, NCID

NB: New Look *Interaction* (see inside back cover)

Letters to the Editor

8 September, 2004

I was most interested in the article “Forced Deinstitutionalisation is the New Totalitarianism” in Issue No 17#3.

For quite some time now, I have been concerned at the almost entirely academic approach to the policy concepts of inclusion and community living that seemed to ignore either the wishes and needs of many of the disabled population.

As a parent and sole carer of a daughter (30 this week) who is both physically and intellectually disabled, I have some experience of disability and believe that:

- a) Whilst “inclusion” is a most desirable aim, it is not always for the betterment of the disabled. There is a definite role for Special Schools and many teachers who teach disabled children in inclusive classes in our educational institutions will admit to this, albeit with reluctance, as they know they are bucking the mainstream philosophy. They can also attest to some of the heartbreak experienced by the disabled in the “normal” environment.
- b) Institutions can be run well and provide excellent support to their disabled clients. One model with which I am familiar has great parental, sibling and volunteer advocacy support which results in a vibrant and happy community in itself. I should perhaps add that staff training, supervision and staff assessment are vital pillars of this particular organisation.
- c) Many of the inclusive models ignore the needs of the severely disabled who, it would appear, have disappeared into the too hard basket.
- d) There are many in the disability “industry” who allow their personal “political” agendas to over-ride the real needs of the disabled.

It can only improve the lot of the disabled if policies and concept debates are more open and acknowledge pitfalls in all models. Thanks for the article.

Yours faithfully,
R. Hefferan

LIVES UNREALISED

An Essay on Society's Responses to Disability

Rob Westcott

PART 1: A Grisly History

Contemporary debate about the best means of assisting people who have a disability is based around principles of social justice and equity. At the dawn of a new millennium, the prevailing view, certainly within the Disability Industry, is that compassion and charity is passé. People with disability should instead it seems, be regarded and treated within a social justice context and yet, at the same time, as clients or consumers of welfare services. These services are, in the current environment, mostly provided by highly structured organisations.

Yet there are inherent contradictions in espousing principles of social justice and equal rights while practising welfare service consumerism. Lip service is paid to notions of normative lifestyles and developing valued social roles for people with disability. But these very same people are non-normatively assessed and programmed, labelled as clients and consumers, placed in special purpose Group Homes and other facilities and, in a variety of other inventive ways, serviced. Thus are they further marginalised and branded as different, if with the best of their professional benefactors' intentions. Within the current conceptual framework there is inadequate scope for addressing the fundamental needs of people with disability. As with all of us, these needs include a sense of belonging, of being cared about, of being liked and loved, and of being regarded as ordinary people (albeit people requiring assistance and, in some instances, discrete supervision). These needs may be less important for survival than food and shelter, but they are no less necessary in order to truly live. While many, if not most people with disability are receiving more and better services, their more abstruse life needs are receiving less, or at least no greater, attention than a century or more ago. People are being processed in a human service context, rather than cared about in a personal and intimate sense. And the gap between those with disabilities, (particularly those with intellectual disability) and those without has not narrowed in any appreciable way as a consequence of the influence and activities of the Disability Industry. In his aptly titled *Inventing the Feeblemind – A History of Mental Retardation in the United States*, James W. Trent Jr. argued:

... the focus on technical and usually psycho-medical interpretation of mental retardation has led to a general ignorance of the maldistribution of resources, status and power so evident in the lives of the retarded. Superintendents, social welfare agents, IQ testers and sterilizers have utilized these psychological and medical paradigms to insure their own social privilege and professional legitimacy. (Trent 1994, Frontispiece).

There has been a shift in power over time. A new set of professionals has replaced the old. Bureaucrats, social theorists and service providers devote the same well intentioned commitment and energy to new service models and theories as did their predecessors a century ago on

sterilisation and segregation. Thus does the Disability Industry continue to worship at the altar of Concepts instead of focusing absolutely on the fundamental needs of the people it is meant to help. After a century and a half of growth, the intellectual disability movement in particular, now a virtual industry in itself, has made itself inevitable. But while elements of this sub-industry are necessary, its overall structure has questionable value to the people it purports to serve, with self perpetuation and superficial accountability its primary, if unrecognised function. Much harm is unconsciously caused to the recipients of its good intentions. In contrast, Trent concludes:

As they did in the 1840's mentally retarded people who have money, supportive relatives and understanding neighbors and employers do well in American communities. As they did in the 1840's mentally retarded people who do not have these things do not. (Trent 1994, p. 268).

The Australian experience is no different. There is compelling evidence to suggest that, as in 1840, the best hope an average, healthy person with a disability has of leading an ordinary and reasonably enjoyable life, is to stay as far away from organised and formalised care as possible. A far preferable alternative is likely to be to receive the necessary supports and assistance from people who genuinely like (or love) and care about them in personal ways. The reality is that this can, and usually must still be obtained in part via human service organisations (particularly in respect of people who have very high support needs), but with the emphasis on people and personal relationships, not distant professionalism and a service-to-consumer mentality. Energy and resources would be far better expended on building and maintaining personal support networks rather than in participating in the mainstream continuum of what is in fact a very grisly history of human endeavour – the Disability Industry.

John Smith, a thirty-year-old man with an intellectual disability living in a six bedroom purpose built Group House in an Australian city in 2004, would be unlikely to be sterilised. He could well, however, be regularly assaulted and intimidated by other residents. He may have to go to work at a sheltered workshop – now relabelled a supported employment program – where he has performed the same menial tasks for more than a decade. He may have an Individual Program Plan which describes his unco-operative behaviour when involved in activities with other residents (none of whom he may especially like or choose to live with) and which requires staff to implement a behaviour management plan to adjust his behaviour. He may have an independent living skills training program with bed-making as the major objective. This may have been task analysed and instruction given, if inconsistently due to turnover of staff, for a year. He may have no real friends, own only his bedroom furniture, and wear cheap and ill-fitting clothes. He is almost certainly referred to and perceived as a client or consumer rather than as a person, and he may have a Case Manager monitoring his life.

His service provider organisation is likely to have been reviewed by business consultants. Typically, these would have been engaged by the service purchaser (the government funding authority) to examine the service provider's administrative and service delivery mechanisms. The consultants would not have been reluctant to claim to have found a range of administrative shortcomings as, for an additional fee, they could then advise the organisation how to fix them. The final review report may have legitimately identified that some residents were inappropriately placed or it may have made cursory criticism of other matters that directly impacted on people's lives. But the organisation, having updated its Policy and Procedures Manual and Business/Strategic Plan and attended to the other perceived administrative deficits, would probably have

met its contractual obligations and been considered efficient and with good management systems in place.

Of course, in a year's time, despite all this apparent activity the only significant change in John Smith's life as a client may be that someone has purchased him a television set or new pyjamas. Change otherwise is likely to be extraneous. John Smith's twin brother without a disability would have a very, very different life. With a shift in attitude within the Disability Industry, plus a number of supportive friends, John Smith could have a life not so different from that of his brother.

Unfortunately, history's relevance to this scenario, and to the current treatment of people with disability generally, is mostly ignored. The brave new world of managerialism and technology in every industry, including welfare, decries history as a mildly entertaining aside. The past is regarded either as distantly tragic or quaint. There is indeed something evocative about the frisson of the freak show, or the image of the amiable village idiot, that is most commonly linked to people with disability of the distant past. But neither these, nor the emergence of institutions, eugenic theory, or medicalisation of care resonate as pertinent to the status quo. And yet to learn and ponder the history of the Disability Industry, and especially its impact on people with intellectual disability, is to understand that the reason people with disability are served the way they are has little to do with what they need or want. It has more to do with belief systems established by early societies that have become deeply ingrained in humanity and the so-called helping professions over subsequent centuries.

If the past is considered at all it tends only to be the recent past. Even this is regarded as being of theoretical or speculative interest and lacking in relevance to contemporary practice. The treatment of people with disability meted out by our ancestors and professional predecessors can now seem so inhumane, so contrary to our present good intentions and technical brilliance that it is dismissed as evil or, at the very least, uncivilised. But it is this contemporary professional arrogance – reflected in the assumption that today's expert is right whereas those of the past were wrong – that enables society to continue the pattern of possessing good (or at least neutral) intentions whilst often instituting or reinventing harmful practices.

People with disability, and especially people with intellectual disability, may seemingly lack characteristics that society values. These include, but are not limited to, intelligence, productivity/usefulness, physical beauty, appropriate social behaviour, self control, communication, and so on. These characteristics have almost always been valued. The corollary is that people with disability have usually, in concomitant proportion, been devalued. Centuries ago the consequences of such devaluation were severe. Infanticide was routinely practised. Children who were unlikely to be productive or were otherwise burdens on their families were left on hillsides, on riverbanks, or in forests to die slowly. Others were killed outright. Survival was difficult enough for the fittest; those with impairments were afforded scant regard and if fortunate enough to survive beyond childhood were tolerated rather than appreciated. Lazar houses, abandoned by their original occupants as leprosy retreated from Europe, served as the first institutions for the new unwanted. Other 'clients' of these services were simply people who were poor, destitute, homeless, chronically sick or elderly. All mixed together, although rudimentary attempts were sometimes made to classify and separate people according to their afflictions.

Life was difficult and times were volatile. The beginning of the second millennium saw both Church and State defending and extending their interests and belief systems. But civilisation

and the discovery of gunpowder, invention of the printing press, and criticisms of organised religion altered established patterns of human existence. In the Twelfth Century, Pope Lucius 111 ordered the first Inquisition to investigate activities that were perceived to be threatening to the influence of the Catholic Church. Through torture and ritualised murder, its emissaries became proficient at exacting confessions, initially of heresy and later of witchcraft.

Hundreds of thousands of people probably died as a consequence of the repressive activities of the Papacy. Burnings at the stake were popular social events. The ‘Sacred Roman Congregation and Universal Inquisition’ continued to torture and murder until well into the Nineteenth Century. It abandoned this title in 1908 but even now possesses immense power in the Catholic Church under the sanitised appellation of the Congregation of the Doctrine of the Faith. Part of its function is still inquisitorial, although ‘witch hunts’ are now confined to wayward theologians and punishments are more in keeping with the standards of the contemporary secular world.

By the late Fifteenth Century, the Church’s experts were able to diagnose witchcraft as well as heresy. In 1486, two Dominican monks produced a book entitled *Malleus Maleficarum*, which roughly translates as ‘Hammer of Witches’. Its impact was profound and long lasting – it has never gone out of print. Medicine had a long gestation before it could offer any objective contribution to the mysteries of madness and functional impairments. Instead, as the pious authors divined, and several generations of subsequent experts upheld, the Devil was at work and the result manifested in people who would today be identified as having epilepsy, cerebral palsy, psychiatric illness and intellectual disability. Their souls had to be saved, communities needed protection, and burning or drowning such witches and those they infected were convenient and indeed merciful solutions. Tens of thousands of people with disorders of the mind died horrible deaths as a consequence of prevailing attitudes, their persecutors convinced they were doing the right thing.

The influence of the Church on the lives of the crippled and the mad was varied. By the Seventeenth Century saintly figures such as Vincent de Paul were rescuing abandoned children and the infirm from the streets of Paris while, elsewhere, his Church brethren in the Inquisition continued to torture and murder. As some families protected and nurtured their disabled offspring, others dealt out dreadful privations. The chief of psychiatry of a hospital in Wurzburg at the end of the Eighteenth Century described among his patients: “A youth of sixteen, who for years had lain in a pigpen in the hut of his father, a shepherd, (and who) had so lost the use of his limbs and his mind that he would lap the food from his bowl with his mouth just like an animal”. Other people admitted to the hospital had, while at home, their “backs beaten blue, with bloody wounds”. (Muller 1798, cited in Shorter 1997, pp. 2–3). The advent of the therapeutic asylum occurred for such reasons – community living for the unproductive fool was rarely idyllic.

For centuries, idiocy was considered to be but one category of the general condition of lunacy or madness. People with significant physical impairments that limited their mobility or ability to communicate, were perceived as crippled idiots. Some distinction between ‘the natural fool’ and the lunatic who ‘hath lost use of his reason’ was evident in English Common Law as early as the Thirteenth Century. But the scholarly entitled and inclined Aureolus Theophrastus Bombastus von Hohenheim, more commonly known as Paracelsus, and Felix Platter, two Swiss physicians prominent in the Sixteenth Century, were the first to make any clear differentiation. Even so, modes of treatment did not diverge until the middle of the Nineteenth Century.

Early institutions were usually places in which to die. Scheerenberger noted: “The death

rate among children placed in either charitable or publicly supported retreats or hospitals was extremely, even unbelievably, high. Of 2,000 infants moved to the Foundling's Hospital of Paris in 1670, seventy-five percent had died within three months. "(Scheerenberger 1983, p. 43). In institutions in Dublin and Paris later in the Eighteenth Century, mortality rates were an astonishing ninety-nine percent and eighty percent respectively.

In France, institutions such as the Hotel Dieux and especially the Bicetre and Salpetriere in Paris accommodated thousands of inmates. These were neither hotels nor hospitals, but disease spreading, foul smelling, terror inducing receptacles for the sick, the poor and the unwanted. In the former:

The patients were herded together in rooms crowded with miserable beds in which they were put without distinction of disease; there were two, four, six, and even twelve people bedded together in various positions; one can easily imagine how sanitary this was! Owing to the conditions of the times, the medical assistance was limited, as was the religious assistance despite the large number of priests and nuns; half of the priests were busy with the church and office work; half of the nuns were so absorbed in their devotions that they overlooked their work, while the other half were too busy to take care of the spiritual needs of the sick. (Giordani 1961, cited in Scheerenberger 1983, p. 43).

By the late Seventeenth Century, Salpetriere:

... housed 7,000 women, all dressed in burlap sack. Five women slept in a bed; the daily diet consisted of one mug of gruel, one ounce of meat, and three slices of bread; and the stench was overwhelming. Over 1,000 mentally disturbed women – 'those deprived of their reason' – were crowded into one wing of the facility, 'in the most deplorable condition when their insanity is the sort that divests them of their instinctive cleanliness. Though the rooms are washed twice a day, these poor souls live in indescribable filth and are like the lowest animals. Mad women subject to fits are chained like dogs to the door of a kennel and separated from the attendants or visitors by a long corridor shielded by grille work. Food is passed to them through the grille work, and straw for their bedding. Rakes are used to remove part of the waste that surrounds them. Conditions at Bicetre, 'the beggars' Bastille', were worse: one felt queasy 'at the entrance from the strong odour emitted by this receptacle for the vilest, foulest dregs of society . . . vicious persons of every kind, swindlers, defaulters, pickpockets, thieves, forgers, pederasts, etc. It is distressing to see them side by side with vagrants, epileptics, imbeciles, lunatics, the aged, and the infirm – known as the 'good poor'. Five or six hundred inmates are packed together there, a tenth of whom are dying. You cannot enter even to bring them food except behind the tip of a bayonet'. (Manceron 1977, cited in Scheerenberger 1983, p. 46).

Conditions in these institutions were horrific. Yet these were human services established by decree of the King of France with the clearly articulated intention of protecting both society and those incarcerated. Less grandiose facilities dotted the countryside throughout Europe but conditions varied little – and barely altered in a century. In a workhouse in semi-rural England in 1776, the elegantly named Doctor William Perfect observed: "a maniacal man they had confined ... He was secured to the floor by means of a staple and an iron ring, which was fastened to a pair of fetters about his legs, and he was handcuffed ... continual visitors were pointing at, ridiculing and irritating the patient, who was thus made a spectacle of public sport." (Perfect

1776, cited in Shorter 1997, p. 3).

And so did legions of the mad endure the Age of Enlightenment. In the Seventeenth and Eighteenth Centuries in facilities throughout Europe, allegedly therapeutic interventions, where they existed at all, were applied mostly to obviously disturbed people and were aimed at shocking them free of their mania. Being pushed through hidden trapdoors into icy water or into snake pits, confinement in coffins, burning of the genitals, and suspension by the arms or legs using ropes and pulleys were not uncommon forms of treatment. Sometimes of course, such methods were successful. Terror is a powerful motivator. The professional application of fear inducing treatment and behavioural conditioning remained for centuries. **It continues to slyly serve as a valued adjunct to reasonableness in the application of many professional programs and human services.**

In the Eighteenth Century, science and medicine replaced religion and superstition as the most influential paradigm in determining how societies viewed and treated people deemed mad or otherwise mentally impaired. With it arrived the era of the professional healer, despite the actual practise of medicine having scarcely progressed in sophistication since the time of Hippocrates. As death has ever been feared, the physical embodiment of curative wisdom – the physician – has ever been revered. A sage like benefactor dispensing an imposing bedside manner and myriad mysterious potions came to offer greater appeal to the suffering than prayer to a distant God. Satanic influences might still be believed to cause many ills, but physic seemed increasingly better placed to ameliorate its effects. But professional help was dangerous. Purging and bloodletting were standard treatments for the assorted quotidian ailments and fevers that especially favoured town dwellers. For those of unsound mind, numerous charlatans and optimistic apothecaries produced a variety of additional illness inducing ‘cures’ ranging from ingestion of mercury to blood transfusions using dogs or calves as unwilling donors. Those patients with defective intellect or personality who survived birth and infancy remained at home so treated, or continued to languish in a variety of workhouses, asylums, gaols and private madhouses.

The more benign private asylums were generally available only to the financially privileged. The first originated in England during the Seventeenth Century. In circumstances to be repeated in the Twentieth Century, most were operated by lay people or pseudo-professionals as profit-making boarding houses. They typically accommodated ten to fifty patients. Ordinary physicians contributed to the advancement of these smaller, private institutions as a means of curing madness. Incarceration became common practice. Eventually, medical practitioners such as Thomas J. Graham would claim that cures could be generally affected in one in three cases in private therapeutic facilities. Such segregation, he suggested, was imperative: “One of the first things to be done in all cases of insanity, under whatever form it may appear, is to separate the patient from his friends and home, as this separation is invariably conducive to recovery.” (Graham 1837, p. 546).

By the Nineteenth Century, Committees of Inquiry began to be commissioned to investigate conditions in public and private asylums throughout England and Europe. In England, a Select Committee was established in 1805 to report to the Secretary of State on the plight of criminal and pauper lunatics. A later such Committee in 1815 called for the compulsory erection of county asylums and a system of public inspection to prevent abuse.

It also reported on the plight of the inmates of London’s Bethlem Hospital. The Sheriff of London had bequeathed his estate to build a hospital for the benefit of those associated with the

Order of St. Mary of Bethlehem in 1247. In 1377, Bethlehem, or Bethlem, Hospital became a mental asylum and in 1547 was acquired by the City authorities. Bethlem was rebuilt and relocated three times, the first because of its proximity to the Royal Palace where the royal personage and entourage were reported to suffer headaches from the constancy of unsavoury noise emanating from the madhouse inmates. The hospital served as an asylum until 1948 and was the only such public facility in England until 1751. It became better known as Bedlam, a now folkloric synonym for chaotic madness.

For two hundred years Bethlem, in its various incarnations, was open to the public as a form of entertainment. (It remains open today in a bizarre but somehow appropriate historical juxtaposition as the home of the Imperial War Museum.) For a small fee, visitors could provoke and be entertained by the antics of the hundred or so clients of this human service. The artist Hogarth immortalised one such scene in *The Rake's Progress*. In a strange twist of charitable benevolence, discharged 'Bedlam Beggars' or 'Toms o' Bedlam' were, by Royal decree, issued with special licenses to enable them to beg in the streets. Their trade must have become lucrative: the licensing system was revoked when too many imposters began to benefit from the advantages.

Within this first public institution in Europe catering for people thought to be mad, existed James Norris. Admitted in 1801, Norris was attached by a twelve-inch chain to a wall of his cell for more than ten years, unable to move his upper arms or body because they were encased in riveted iron bars weighing a quarter of his own body weight. He remained chained to the wall until only weeks before his death in 1815. Inmates of institutions experienced years of such physical restraint without respite.

In *Museums of Madness*, Andrew Scull describes James Norris' long confinement at Bethlem as exemplifying the long tradition of tension between service providers and reformers:

The most curious aspect of all this was not that a man should be found confined in such a fashion – for there can be no doubt that numerous analogous situations existed at the time. Rather it lies in the response of the hospital authorities. Compelled to institute an official inquiry, the Governors conceded that the facts were as the reformers had stated them, but contended that the confinement was kind and merciful rather than cruel and brutal, and expressed their undiminished confidence in the asylum's medical officers. One can place two possible interpretations on this bizarre state of affairs. Either the Governors shared the callousness of their subordinates and were ingenuous enough to let this show. Or their protestations were sincere, and they genuinely saw nothing wrong with treating a lunatic in such a fashion. The latter is surely the more plausible. (Scull 1979, p. 66).

This also illustrates one of the fundamental contradictions in the nature of human service. Human beings are complex creatures. The German poet Goethe had his character, Faust, exclaim: "Two souls, alas, do dwell within my breast!" The capacity to commit good and evil acts can be equally present in anyone and particularly in those who have experienced professional indoctrination. Much of this capacity can be unconscious and much can be the result of social conditioning. Even the consequences of the most vicious and inhuman acts can be rationalised and 'derealised' by the perpetrators and others. In his definitive study of German doctors under Hitler, Robert Jay Lifton eloquently described a process of what he termed derealisation and disavowal that afflicted the medical profession in concentration camps such as Auschwitz in the 1940's. The doctor could be both healer and killer, and through what Lifton called 'psychic numbing',

some could be equally efficient and see value in committing both activities contemporaneously without recognising any contradiction. The keepers of James Norris were similarly oblivious to the contradictory duality of their actions. They were his protectors yet also his *bête noir*.

Bethlem Hospital was an evil place. Yet it would be too easy, and inaccurate, to portray this or any other institutions' managers as deliberately evil or inherently incompetent. James Norris was by all accounts a most difficult inmate. He was violent and dangerous and cunning and had viciously assaulted other inmates and attendants on numerous occasions for four years. He was able to slip out of less restrictive devices than that eventually and exclusively designed for him. He was indeed regarded as a beast, but at the same time nobody seemed able to produce an effective less restrictive alternative. For four years they had tried. His iron body cage was a sign of the ultimate frustration of his carers more than pure evil. It is more palatable to accept the latter explanation, however. If evil acts emanate not from evil people but from the good intentions and fallibility of ordinary people, what might this say of all of us?

James Norris' plight was not exceptional. Bethlem Hospital seems to have been typical of such facilities at that time. But even in these places attempts were made from time to time to make life more bearable. Even Norris was allowed books, newspapers, and a cat. James Matthews, a contemporary of Norris, also spent many years at Bethlem. Unlike Norris, Matthews had a room with numerous comforts including candles and materials for drawing and writing, and he was taught engraving. The stated aims of Bethlem Hospital, certainly by the early Nineteenth Century, were to cure and not unnecessarily confine lunatics, and attendants were instructed to act kindly and humanely. Were the Governors of Bethlem therefore unreasonable in their defence of themselves and their facility? They thought not.

The Age of Enlightenment did herald the beginning of a philosophical transition. Madness had been characterised as akin to animality in man, with control and indiscriminate brutality the appropriate treatment as exemplified by the attitude of the Governors of Bethlem toward James Norris. To reformers though, the mad person was still a person and, while witless or lacking self control, could have his or her faculties returned with proper treatment.

One early manifestation of change in the business of service delivery was evident in the machinery of madness. In most institutions, simple if terrible mechanisms of restraint such as chains, iron cages and manacles gradually gave way to allegedly therapeutic devices of various styles. Gyration chairs, whirling beds, and hollow wheels large enough to accommodate the unfortunate patient were used regularly and with enthusiasm. Patients could be strapped in and rotated at speed, the intention being to restore blood flow to the brain or shock the person out of their aberrant state. Water cures were commonly attempted. Patients might be restrained in wooden bed-like tubs and have countless buckets of water thrown over them, or be strapped in chairs, or spreadeagled on the floor and have the same treatment applied from high above. Thus did hydrotherapy establish its place in the lexicon of disability.

In the world of academia, the history of madness is rarely one that has been lacking in reformist enterprise. As early as the Eighteenth Century experts had emerged to establish their reputations as mad doctors of eminence. The Englishman William Battie, and the Italian Vincenzo Chiarugi were followed by the likes of Pinel and Tuke, and later Esquirol, who came to be regarded as the crown prince of therapeutic psychiatry. All advocated their own form of reform. All published professional treatises extolling the virtues of systemic organisation and a professionalised culture.

As the Eighteenth and Nineteenth Centuries passed, social and living conditions for most people with disability remained largely unchanged despite government inquiries and legislation and a growing army of self-proclaimed experts. Tuke, founder of the York Retreat, described the plight of those remaining outside the more specialised institutions:

Hardly a parish of any considerable extent in which there might not be found some unfortunate human creature, who, if his ill-treatment had made him 'frenetic', was chained in the cellar or garret of a workhouse, fastened to the leg of a table, tied to a post in an outhouse, or perhaps shut up in an uninhabited ruin; or, if his lunacy were inoffensive, was left to ramble, half-naked and half-starved, through the streets and highways, teased by the rabble, and made the jest of the vulgar, ignorant, and unfeeling. (Tuke 1882, cited in Scheerenberger 1983, p. 65).

Conditions in continental Europe differed little from those in England. France suffered political turmoil for the first half of the Nineteenth Century, as did Germany and Italy prior to achieving nationhood. Political upheaval had deleterious effects on all aspects of society but was especially damaging to the most disadvantaged. No longer were the burdensome transported from city to city through the waterways of Europe on the notorious *Narrenschiffe* or 'ships of fools'. But their destination in another sense, and their future, were as uncertain. Throughout the Western world, the vast majority of people with disability continued to live with family members well into the Nineteenth Century, and their circumstances varied accordingly.

Only in Belgium was there a significant departure from the norm. At Gheel, a comparatively sophisticated boarding-out scheme operated where local villagers took in the insane. With its reported genesis late in the Sixth Century, Gheel became a Mecca for the lunatic. While some patients were hospitalized, the vast majority – over a thousand by the 1850's – lived with local families who were paid for their hospitality. The care provided could be less than ideal and there were many attempts over many years to regulate and license carers. Some other bold experiments in community care based on the Gheel experience evolved in the Eighteenth and Nineteenth Centuries particularly in Britain and North America. Their regulation by officialdom had a remarkable similarity to that of the latter part of the Twentieth Century.

Glimpses of compassion and caring were evident from time to time and civilisation, and the desire to improve the human condition, produced the first signs of a transition to organised education and care for that sub-category of the mad identified as idiots. The capture of Victor, the Wild Boy of Aveyron, in the forests of southern France in 1798, had caught the attention of authorities elsewhere. Entrusted to the care of Jean-Marc-Gaspard Itard, a pupil of Philippe Pinel, Victor received five years of intensive and individualised education. Itard published two reports on his work incorporating what may have been the first ever Individual Program Plan.

As summarised by Scheerenberger, Itard's five aims for Victor's education were as follows:

1. To interest him in social life by rendering it more pleasant to him than the one he was just leaving ...
2. To awaken his nervous sensibility by the most energetic stimulation, and occasionally by intense emotion.
3. To extend the range of his ideas by giving him new needs and by increasing his social contact.
4. To lead him to the use of speech by inducing the exercise of imitation through the imperious

law of necessity.

5. To make him exercise the simplest mental operations upon the objects of his physical needs over a period of time, afterwards inducing the application of these mental processes to the objects of instruction.

(Scheerenberger 1983, pp. 76–77).

Despite Itard's efforts, Victor died in his forties in 1828 still "fearful, half-wild, and unable to learn to speak" (Lane 1976, cited in Scheerenberger 1983, p. 77).

Edouard Seguin, a student of Itard, had the greatest subsequent impact on philosophy and educational approaches to idiocy. His text, *Idiocy, and its Treatment by the Physiological Method*, introduced positive reinforcement and imitation/modelling, essential ingredients of contemporary professional obsession with formalised independent living skills training. Seguin opened the first ever school for idiots in 1839, and in the process introduced the first phase in the systemisation of services solely for people with intellectual disability. Reports, undoubtedly exaggerated, of astonishing successes flooded the fledgling Idiocy Industry. To escape political persecution, Seguin migrated from France to North America a decade later and carried with him the seed of a noble ideal – the residential school for idiots.

By the 1840's, Seguin's work, together with that of a number of his contemporaries in both Europe and North America, inspired others to challenge the custodial nature of most existing lunatic asylums. For the first time, there commenced a concerted effort by an increasingly numerous, influential, and powerful body of men to establish specialised residential institutions for the feeble-minded and the crippled. There was a genuine sense of philanthropy and real hope that idiocy was possibly curable or could at least be ameliorated through education and regimented care.

As in Europe, madness in all its manifestations had afflicted the New World. European attitudes had been transplanted in North America from the time of the first settlements in the Seventeenth and Eighteenth Centuries. The same problems emerged as the population increased with the same solutions advocated. Medical treatment was inventive but rarely effective. Early physicians promoted benign therapies including the use of herbs such as St. John's wort. Others gave sanguine endorsement of the medicinal properties of frog's spawn, crab's eyes, and earthworms or dog lice mixed with perspiration or saliva.

In 1662, the first almshouse had been established in Boston. As with generic asylums everywhere it became a repository for that community's undesirables. The crippled and the feeble-minded mixed with the mad, the sick, vagrants, paupers and the elderly. In 1692, the infamous witch trials of Salem resulted in two hundred people being convicted of witchcraft. From eyewitness accounts, it seems a number were people who, in other circumstances, might have been regarded merely as innocent simpletons.

Most people considered mad lived with their families in their local communities. In Massachusetts, in 1693, new laws enabled the provision of poor relief for idiots. A full century later in Kentucky a pauper idiot law was enacted providing for a small subsidy to families with an idiot member. In the intervening years, other states adopted similar community based support measures on a piecemeal basis. People considered difficult, or who had no independent means and greater need, were deposited in local gaols, almshouses, or poor farms, and this continued to be the case for most of the first half of the Nineteenth Century. Some were auctioned or boarded

out to perform menial tasks in exchange for food and shelter. The first lunatic asylums, such as the Pennsylvania Hospital, opened their doors on Sundays and crowds flocked to view the spectacle provided by the inmates, much as they had at Bethlem and other hospitals in Europe.

Legislators and public alike were occasionally embarrassed by reports of abuses and by 1850 two small residential schools for idiots had opened in Massachusetts under the direction of Samuel Howe and Hervey B. Wilbur. Howe subsequently wrote *The Causes of Idiocy*, an immensely influential text that was still oft quoted over half a century afterwards. He expressed the belief that idiocy could be prevented and/or cured if the human race followed the laws of God and behaved itself. Degeneracy would otherwise beget degeneracy.

Positive publicity concerning the work of Howe and Wilbur, much of it self generated, resulted in several other American states opening residential training schools over the next two decades. By 1870 Ohio, Connecticut, Kentucky, Illinois, New York and Pennsylvania had all established facilities specifically for the feebleminded. Newspaper and journal articles, extolling the successes of these programs, generated increasing interest from families. Demand outstripped availability of services. Community leaders and influential citizens clamoured for more. The earliest facilities were small in size, were located within towns and cities, and were frequently conducted in such a manner as to minimise the negative effects of institutionalisation. The intent was to educate if not cure, and to then return the individual to society.

Reformers honed their professional ideology on their feebleminded charges. This was a new movement, vaguely medical and educational in character, but at the same time with its own flavour. Idiocy began to be defined and categorised. Wilbur identified four levels: simulative, higher grade, lower grade, and incurable. But with intelligence and social conformity ranking ever higher in the opinion of the educated, it was inevitable that idiocy also became further identified as a distasteful sub-classification of humanity located on the fringes of acceptability. Idiots and the feebleminded were stupid and thereby deserving of pity and charity, but they also represented gluttony, self abuse, and an aberration of nature that should be dealt with by a civilised and educated society.

Thus compassion and revulsion combined with discipline and education to create an increasingly professionalised environment in which the values and attitudes of a few very powerful individuals utterly dominated the lives of other highly vulnerable individuals. The trend was set. No longer were the feebleminded and crippled to be neglected or abused in almshouses, gaols, or large asylums housing all of society's unwanted; they were to be remorselessly educated in special institutions with firmness, discipline and order their constant companion.

The zeal of the reformers was remarkable. Figures such as Samuel Howe and Dorothea Dix became icons of philanthropic endeavour. Human betterment was their goal and they pinned their reputations on, and devoted their lives to, their mission. It seems most unlikely that they were motivated by anything other than a genuine desire to save people from misery and improve humanity. Yet their very enthusiasm created a legacy that may never be undone. While Samuel Howe undoubtedly saved people's lives by removing them from cells and cages and worse, he was greatly influenced by phrenology (he would not employ a domestic servant until she removed her bonnet so he could examine the shape of her head), and he was also insistent on the need for special segregated training facilities.

Dorothea Dix, the most persistent advocate for idiots of her generation, saw degeneracy of

the parents as being almost the sole cause of the condition. She is credited with having been responsible for the establishment of more than thirty institutions for the mentally ill. She was particularly opposed to the feeble-minded remaining at home even when in the most positive of circumstances. Her vision was the gathering together of all those afflicted in order to receive ‘proper care’ – except for black slaves and natives whom she judged were lacking in ambition and therefore not prone to insanity. Other influential figures developed similarly curious combinations of beliefs. Ironically, it was Samuel Howe who said: “Nowhere is wisdom more necessary than in the guidance of charitable impulses. Meaning well is only half our duty; thinking right is the other and equally important half” (Howe 1866, cited in Wolfensberger 1975, pp. 18–19).

Enthusiasm for social change quashed personal reflection. Conditions in generic facilities such as almshouses were appalling, educational advances were encouraging, and to be charitable was a popular duty among the genteel. Compulsion to civilise society produced monuments to social order and the architect designed, purpose built residential institution evolved as one such symbol. Such facilities began to dot the rural and outer urban landscape throughout North America. They increased in number and replaced rented city buildings that were originally used for education and training purposes. Architects, builders and local dignitaries were eager to construct the best and most modern facilities. As experts weeded out more and more of the feeble-minded and congenitally unfit, demand for institutions grew. Despite increasing pressures on the system, an emphasis on education and rehabilitation remained for some time. And a degree of success must have been achieved. Some ten to forty per cent of those institutionalised were reportedly returned to the community in the United States between 1860 and 1890, a figure comparable to that of a century later.

The middle of the Nineteenth Century therefore saw substantial changes occur, both in Europe and North America, in the way in which the feeble-minded were regarded and treated. From neglect and abandonment grew hope and industry aimed at saving, educating and then, where possible, rehabilitating people to the community. Mixed with these initially noble ideals were ill thought out practices of an increasingly systemic nature. The dominant theory among experts and civic leaders, its legacy remaining today, seemed to be “We can care for more lunatics and idiots if we congregate them, and organise ourselves”.

As reformist institutions expanded in size and number, so too did the power and influence of the experts. But in the absence of scientific evidence concerning aetiology and treatment, strange theories abounded. Seguin believed a major cause of idiocy in male offspring was drunkenness of the father at the time of conception; in females the mother was likely to have been the culprit. Many contemporaries identified alcohol abuse as a cause only in respect of the father. Where alcohol in the father was not a factor, emotional problems of the mother might be identified as the cause. An 1886 report to the American Association on Mental Deficiency by its Committee on Provisions for Idiotic and Feeble-minded Persons listed causes such as “maternal anxiety and over-tax” and “unsuitableness of the parties in contract to live with each other.” [ie. unhappy marriages] (AAMD 1886, cited in Scheerenberger 1983, p. 113). Lack of real knowledge did not deter professionals from expounding theories.

In 1884, Isaac Newton Kerlin contributed a fourth ‘scientific’ category to the accepted classification of intellectual functioning. Idiots, imbeciles and the feeble-minded were not enough. Thus was the moral imbecile invented, the label applied indiscriminately, and thousands more people headed for confinement in institutions. Kerlin claimed:

... these moral monstrosities are often conceived and born in the best of families; inheriting graces of body and precocious in accomplishments, there is an inherent failure to recognise the claims of others, which is the foundation of duty, truth, respect for property, prudence, discretion, and all the primary virtues of civilized societies: in this declension consists the essence of moral insanity and imbecility. (Kerlin 1884, cited in Scheerenberger 1983, p. 111).

By the 1870's, further shifts in attitude were becoming apparent. The hopefulness of the 1850's expired. The feeble-minded became a burden and ultimately a menace. The early over-reported successes of small idiot schools in the 1850's were replaced by a sense of frustration and fear for the future of the human race. Despite obvious improvement in some individuals, more and more idiots were being identified in the population. As the Industry developed, so did its capacity to create more of a problem and thus perpetuate itself. Kerlin, inventor of the moral imbecile was, as we shall see, later upstaged by Henry Goddard who 'discovered' the moron.

In 1874, Richard Dugdale, a member of the Executive Committee of the Prison Association Of New York, identified members of four interrelated families in one prison. On investigation, many others of the same family were discovered to have had a close association with the prison system. Known as the Jukes, Dugdale traced their family history and claimed to have studied six generations or over 700 family members. Most, he reported, had all the attributes of degeneracy with many lacking intelligence, possessing deformities, practising prostitution and petty crime, abusing alcohol, and suffering a variety of ailments such as syphilis and scrofula. His research was immediately taken to demonstrate that insanity, feeble-mindedness, degeneracy and criminality, were interrelated and largely hereditary.

Dugdale estimated that hundreds of millions of dollars had been lost to the national economy because of the Juke family and their kind. And the problem, he claimed, was multiplying. The 1880 census conducted in the United States revealed there were 91,997 insane persons in a total population of 50,000,000. When compared to 15,610 in a population of 21,000,000 in 1850 the obvious deduction to be made was that the rate of insanity and idiocy was doubling with each generation. (No consideration was afforded the alternative possibility that diagnosis/assessment and statistical measures were flawed.)

Such sentiments led to the first organised and deliberately punitive phase in the treatment of people with intellectual and other disabilities. Experts and social commentators became shrill in their advocacy for incarceration and restriction. Osborne, in 1894 observed:

Here is an ever increasing army of incompetents becoming as they breed, still more incompetent and irresponsible, still more destructive; ever more and more debasing and depressing alike upon the body politic ... Walk any of our large cities and you touch arms with all sorts of mental abnormalities, some harmless, some harmful, but all pitiable, and betrayed by the eccentric gait, the neuropathic eye and the other signs, which you as specialists may read even as you run. Mental blights linked to the intensifying influences of poverty and physical distress skulk threateningly in the rear, while in your path you brush by many slumbering mental volcanoes that only wait some peculiarly exciting stimulus to make them burst forth their murderous, ruinous fires. (Osborne 1894, cited in Scheerenberger 1983, p. 117).

By the end of the Nineteenth Century, increasing numbers of people with various forms

of disability were being placed in isolated institutional communities throughout the United States in particular. As the trendsetter of the Western world, the philosophy of segregation and incarceration practised there became firmly embedded everywhere. Experts became more and more strident in their promotion of the concept of permanent institutional care. They had negligible opposition despite accounts of terrible conditions in institutions that occasionally pricked the public conscience.

Their position was aided by simplistic interpretations of the work on heredity of men such as Charles Darwin and Gregor Mendel. The former became, and remains famous for his *Origin of the Species* published in 1859; the latter, an Austrian monk and botanist, published the results of his experiments on garden vegetables in 1868. So influential were his discoveries, they became known as Mendel's Laws. The study of genetics became a passion of the layman and the pseudo-scientist. Everyone had an opinion and all pointed toward a bleak future for the human race unless the menace of the feeble-minded and congenitally crippled could be solved, and their apparent propensity for producing more and more flawed offspring halted.

In 1869, Francis Galton, a cousin of Darwin, published *Hereditary Genius*. Twenty years later he wrote *Natural Inheritance*. Dangerously intelligent, rich, and with little else to do, Galton became obsessed with the measurement of things. He was the father of the science of statistics, the process of analysing allegedly quantitative data that now largely rules our world. Galton was mightily impressed with the power of numbers. He applied his considerable deductive imagination even to that which patently could not be quantitatively reasoned. The supposedly scientific measurement of the unmeasurable is today reflected in intelligence testing, assessments of service quality and, most recently, attempts to measure quality of life. Over a hundred scales measuring quality of life have been produced by an assortment of experts in recent years because it is fashionable and based on a humanitarian ideal.

But Galton was the most ambitious of all. He tried to measure degrees of boredom (as suggested by the fidgeting of members of the Royal Geographic Society during lectures), the efficacy of prayer, and even the population distribution of beautiful women. For the latter he devised a pocket sized wooden cross with a piece of paper attached which, unobserved, he would deftly prick with a needle held between finger and thumb as he passed women in the street. The cross was divided into three sections – one each designated “attractive, indifferent, and repellent” – allowing him to later translate his data into a ‘beauty map’ of Britain. He concluded that London ranked highest and Aberdeen lowest.

Galton may, by today's standards, appear eccentric and whimsical if not disturbed. But his was a serious business and a powerful intellect – the American psychologist Lewis Terman estimated Galton's IQ at over 200. People queued outside Galton's laboratory to have their intelligence assessed according to criteria he established based on cranial and body measurement. He was judged an expert and his musings as scientific fact. Galton was lauded by his contemporaries, and by those who followed. He was:

... the true father of the mental test and of all that later sprang from it – of the practical application of testing to problems of deficiency and aptitude, of vocational guidance and selection, of statistical analysis and the discovery of factors by the correlation method ... Never again in the history of the science (of psychology) up to the present time do we meet an investigator so brilliant, so versatile, so wide in his interests and abilities, so little bound by prejudice or preconception ... Men of Galton's temperament are comparatively

rare in the world of science, for they seldom possess the qualities necessary for the development and employment of truly scientific methods. Modern psychology as an independent science is fortunate in having such a man, and one of such calibre, in its brief history. (Flugel 1933, p. 132).

Galton's mind was rarely still, flitting from project to project. Yet he was no dilettante. He was deeply interested in evolution and in 1883 coined the term 'eugenics' to describe the study of human breeding. With it he introduced a concept that became an instant hit. Though not his intent, it would ultimately result in the organised murder, mostly by the medical profession, of tens of thousands of people with disability. Essentially, eugenics was Mendel's Law concerning physical inheritance of all organisms, applied to the intellectual and physical inheritance of the human race. Galton claimed that as abilities were inherited, so too were disabilities, particularly those of a sociopathic nature.

As a link between feeble-mindedness and crime, pauperism, disease, and anything degenerate became steadily and fraudulently embedded in scientific circles, the eugenics scare gathered pace. Throughout North America and Europe, Eugenics Societies emerged as part of a broader social hygiene movement. Galton produced a journal of eugenics, *Biometrika*, the first issue appearing in England in 1901. In 1907 he became President of the Eugenics Education Society, which was originally established by a Mrs. Gotto, a committee member of a group known as the Moral Education League. He died in 1909. But his legacy lived (and still lives) on.

In the United States, the American Breeder's Association in 1913 suggested:

... (the) following classes must generally be considered as socially unfit and their supply should, if possible, be eliminated from the human stock if we would maintain or raise the level of quality essential to the progress of the nation and our race: (1) the feeble-minded, (2) paupers, (3) criminaloids, (4) epileptics, (5) the insane, (6) the constitutionally weak, (7) those predisposed to specific diseases, (8) the congenitally deformed, and (9) those having defective sense organs. (American Breeders Association 1913, cited in Scheerenberger 1983, p. 113).

The Association considered options such as arranged marriages, polygamy, segregation, sterilisation and euthanasia to build up the stocks of the healthy and intelligent and reduce the capacity of the degenerate to procreate.

A year before, Henry Goddard, an ex-high school principal made Director of the Vineland Training School, published his study of the Kallikaks. Deborah Kallikak had been born in an almshouse but was admitted to Vineland at the age of eight. On investigating her family history, much as had Dugdale investigated that of the Jukes, Goddard established that six generations previously, Martin Kallikak had a brief relationship with a feeble-minded woman. She produced a son, who in turn produced 408 direct descendants, of whom one hundred and forty-three were allegedly feeble-minded, thirty-six were illegitimate, thirty-three were sexually immoral (i. e. prostitutes), twenty-four were alcoholics, three were epileptic, eighty-two died as infants, and three were criminals. Forty-six were apparently normal. Martin, some years later, married 'appropriately', and from that union produced 496 descendants, only four of whom were in any sense degenerate. Of the remainder, there were judges, doctors, teachers and any number of respectable citizens.

Some of Goddard's observations have recently been exposed as fraudulent. Original

photographs of members of the Kallikak family had been re-touched to give the impression of feeble-mindedness. But, at the time, his research confirmed what was already believed: feeble-mindedness and associated degeneracy was a spreading abscess on the soul of humanity. Goddard was also an inveterate tester of intelligence. He believed passionately in the value and scientific validity of measuring mental acuity. He conducted a study of new immigrants as they arrived at Ellis Island, the gateway to the United States. Binet intelligence tests were conducted on four groups. Goddard was perplexed to discover that, according to his tests, eighty-three percent of the Jewish immigrants tested were feeble-minded, along with seventy-nine percent of the Italians, eighty percent of the Hungarians and eighty-seven percent of the Russians. Could this be true he wondered? He had used all due care and scientific rigour in his assessment but it seemed implausible – who would believe that four-fifths of the population of other nations were of subnormal intelligence? Eventually he massaged the figures and left out some test results and the numbers decreased to a more acceptable forty or so percent.

By the beginning of the First World War, any compassion previously felt for the feeble-minded and congenitally crippled had disappeared in something approaching a frenzy of fear. Whipped up by the crusading rhetoric of the experts, now also armed with the first comprehensive IQ tests introduced by a German, William Stern in 1914, the menace of the feeble-minded and deformed was entrenched. Segregation into larger and more numerous institutions was assured. Any pretence at education leading toward a return to community life had long since been abandoned. People suspected of feeble-mindedness due to speech or other defects were institutionalised regardless of their true condition. Kuhlmann, also an active figure in intelligence testing, suggested that one percent of the population were feeble-minded. Many institutions would be needed.

The experts waxed lyrical. Terman, renowned for his own work on the measurement of intelligence, said in 1916:

... not all criminals are feeble-minded, but all feeble-minded are at least potential criminals. That every feeble-minded woman is a potential prostitute would hardly be disputed by anyone. Moral judgement, like business judgement, like social judgement, or any other kind of higher thought process, is a function of intelligence. Morality cannot flower and fruit if intelligence remains infantile. (Terman 1916, cited in Scheerenberger 1983, p. 153).

Shortly before the United States entered the First World War, Goddard announced his discovery of the moron:

Of late we have recognised a higher type of defective, the moron, and have discovered that he is a burden; that he is a menace of society and civilization; that he is responsible to a large degree for many, if not all, of our social problems. (Goddard 1915, cited in Wolfensberger 1975, p. 34).

The combination of IQ testing and expert classification/diagnosis eventually led to the calamitous 'discovery' that almost half of the US troops despatched to the battlefields of France in 1917 were allegedly feeble-minded. The implication – that half the population of the United States of America could never match the intellect of a twelve-year-old – was unthinkable yet apparently scientifically proven.

As the American Breeders Association had suggested they should, expert minds turned to developing strategies to deal with the blight of feeble-mindedness and its impact on the future of the human race. While the seed of systemic euthanasia found insufficiently fertile ground in which

to germinate in the United States, segregation of the sexes in institutions, restrictive marriage laws, infanticide by stealth, and sterilisation did. Thirty-nine states passed laws prohibiting or allowing for the annulment of marriages involving feeble-minded people.

Sterilisation, together with institutionalisation, became the preferred strategy of the Industry. How to institute the practice methodically enough to halt unhealthy procreation was problematic. Some experts felt it was simply not feasible, however desirable. Nonetheless, thirty states developed laws allowing, or in some instances requiring, sterilisation of the unfit. Tens of thousands of people were sterilised, many oblivious to their fate. Many more volunteered for the procedure as the only means of gaining their freedom or being paroled from the institution. A large proportion of the inmates of these institutions who were sterilised in fact were simply illiterate, or had physical deformities and were from the poorer classes. Intelligence testing was, and is, an inexact pseudo science and many admissions were in any case made according to the judgement of local medical practitioners and magistrates. Involuntary eugenical sterilisation was still being practised in the United States as late as 1976.

Laws permitting or requiring involuntary sterilisation were passed in numerous countries including Canada, Germany, Denmark, Finland and Sweden. Many more, including Australia, came close to enacting legislation. Advocates were so focussed on what they perceived to be their eugenic duty that they ignored the human tragedy. As with the Governors of Bethlem Hospital a hundred years earlier, these people were not inherently evil. Their essential humanity had simply been displaced by their drive to maintain the human race in a healthy state and, in particular, to save it from intellectual extinction.

The once impregnable arguments that heredity was the cause of feeble-mindedness, that feeble-mindedness and vice were inextricably linked, and the demise of the human race was inevitable without radical social engineering, first began to lose favour in humanitarian circles. A survey in an institution in England found that fewer than eight percent of the patients had 'defective' parents. The worldwide depression of the 1930's also saw many more people resort to crime and anti-social acts than those perceived as feeble-minded. Sterilisation on a large scale was not practical and was to some extent distasteful. Holes were appearing in the theories of impassioned eugenicists and social hygienists, though the impression of looming human calamity lingered and lumbered along of its own volition for some time.

This was enough to keep the search for solutions alive. If the burden of the feeble-minded and congenitally weak could not be resolved, could it perhaps be removed? Euthanasia could not be countenanced by civilised nations, at least not en masse – or could it? Certainly it was considered everywhere. As early as the late Nineteenth Century, eminent scholars had written for the British Westminster Review outlining the merits of destruction of the insane in order to remove the encumbrance on humanity. In 1912, the Hungarian Psychiatric Society heard papers from their members calling for legislation to enable the euthanasia of useless idiots. Switzerland and Denmark drafted involuntary euthanasia laws in the 1920's. In 1932, the President of the British Society of Medical Officers proposed euthanasia legislation.

In America, the Nobel Prize winning Alexis Carrel argued for establishment of state-run euthanasia centres where insane people could be economically and painlessly killed. The Chamber of Doctors in Illinois sought government approval for mercy killing. As late as 1942, Doctor Kennedy, a Professor of Neurology and member of the American Psychiatric Association, called for the killing of feeble-minded children over five years of age. The people of the United States, as

evidenced by a 1937 poll, were also leaning toward drastic solutions. Forty-five percent agreed with euthanasia for defective children. However, governments, with their propensity for taking the middle ground, were reluctant to act. There was no realistic solution, just a vast problem.

The only options offered were permanent segregation and incarceration, and ongoing attempts to implement measures of mass sterilisation. The Industry appeared bereft of fresh ideas and passions. “Where to from here?” might well have been the cry emanating from the throats of a thousand institution superintendents scattered across the globe. In the meantime, the inmates of a thousand institutions woke in the mornings in cold barn-like wards, were hosed down before a breakfast of gruel, wandered aimlessly around the dank, stinking halls dressed in clothes made from sacks, and went to bed again at three o’clock in the afternoon, at best ignored and more likely ridiculed or abused by their carers. Those most fortunate continued to work in the institutions’ workshops or vegetable gardens. Those less so died comfortless.

In one very civilised, very organised nation the problem was, however, to be removed. Here there was enthusiasm, passion, and a noble ideal to pursue. Medical practitioners, academics, special educators, judges and lawyers, politicians, social commentators, and civic leaders were of like mind – or at least not disposed to protest in any cohesive way. A difficult task was about to be performed but one that would ultimately be to the profound advantage of mankind and merciful to the afflicted. Genocide.

Some background is necessary. In the Nineteenth Century, Germany had established a reputation as a showpiece of psychiatric liberalism. And, by the beginning of the Twentieth Century, it was certainly no worse than any other civilised nation in the way it treated the insane, the feeble-minded and the congenitally weak. Most people with mental afflictions lived with their families, but a substantial and increasing number were placed in psychiatric institutions. But in these institutions, as in North America, any notion of education or rehabilitation had long since been abandoned. The pseudo-science of eugenics reigned and the power of the psychiatrists was absolute. If the public considered those with weaknesses of the mind at all, such *untermenschen* were perceived as, at worst, a danger to the future viability of the human race and at best as useless to, and a drain on, an emerging economy. It was in such a climate that Germany’s feeble-minded, with the rest of the world, entered the maelstrom of The Great War.

The impact of the 1914–1918 conflict changed the political and social face of the Western world forever. Millions of people died, governments collapsed and empires disappeared. The welfare of marginalised groups such as the feeble-minded and the insane was immaterial. Death rates in mental institutions throughout Europe climbed dramatically during the war years. Governments lacked funds and interest to expend on the useless, and even maintenance in the perceived relative safety of asylums seemed somehow obscene when the flower of the nations’ youth was dying on the battlefields. In Germany particularly, rations were cut, staff transferred to more essential duties, and conditions became increasingly overcrowded as facilities were commandeered for the war wounded. 140,000 residents of German psychiatric institutions died during the First World War. Allowing for natural attrition this represents a third of the pre-war institution population dying from lack of care, disease and starvation. As Germany suffered an economic blockade for much of the war these figures were higher than for other countries. The same attitudes, and the same pattern of neglect, nonetheless applied everywhere.

As the world rebuilt itself in the 1920’s, so too did institutions partly regenerate. For a time the plight of the shell-shocked returning from the war attracted public sympathy. But there

remained an undercurrent within professional circles that the feeble-minded and the insane were a parasitical class and a social burden. In the ruins that were post-war Germany, Karl Bonhoeffer in his 1920 Presidential address to the German Psychiatric Association said:

It could almost seem as if we have witnessed a change in the concept of humanity. I simply mean that we were forced by the terrible exigencies of war to ascribe a different value to the life of the individual than was the case before, and that in the years of starvation during the war we had to get used to watching our patients die of malnutrition in vast numbers, almost approving of this, in the knowledge that perhaps the healthy could be kept alive through these sacrifices. (Bonhoeffer 1920, cited in Burleigh 1994, pp. 11–12).

Also in 1920, Karl Binding and Alfred Hoche published *Permission for the Destruction of Life Unworthy of Life*. Binding, a leading constitutional and criminal lawyer, and Hoche, a Professor of Psychiatry, argued in favour of euthanasia especially in relation to those individuals judged to be ‘useless eaters’. Such an act could be viewed as an act of healing and a mercy death. Idiots in particular were not merely worthless but were deemed to be of actual negative value. They were a burden on the state as well as their families. Their death would save them the agony of other people’s cruelty and would free the economy of an intolerable burden. They were animal-like, “travest(ies) of real human beings, occasioning disgust in anyone who encounters them” (Binding & Hoche 1920, cited in Burleigh 1994, p. 17). Binding and Hoche argued that, while society may be squeamish of organised euthanasia, this attitude could change with time. Elimination of the unfit would prove to be beneficial to all. As medical practitioners would oversee selection, the practice could be instituted and monitored scientifically.

Economics and racial politics became increasingly influential in shaping the direction of professional doctrine. This was particularly evident in Hitler’s Germany where pressure mounted to reduce the cost burden imposed by misdirected welfarism. Over 200,000 feeble-minded people were sterilised in Germany between 1933 and 1939. Until the United States entered the Second World War in 1941 enthusiastic eugenicists from that and other countries visited Berlin and Germany’s regional asylums to study and report on developments aimed at combating insanity and feeble-mindedness. Many were clearly impressed, one representative from the State of Virginia observing with reluctant admiration that Germany was beating the United States at its own game.

Hitler’s views concerning the feeble-minded and congenitally weak were an enhanced reflection of prevailing scientific and social theory in Germany and overseas. In 1939, he instructed his personal physician, Doctor Karl Brandt, to investigate the case of a Party member who had petitioned to have his handicapped child killed. Brandt reported back to Hitler that he found “a child who was born blind, an idiot – at least it seemed to be an idiot – and it lacked one leg and part of one arm” (Brandt 1939, cited in Gallagher 1990, p. 47). Hitler apparently instructed him to arrange for the child to be killed as an act of mercy, and to ensure neither the family nor their doctor could be prosecuted under German law. The father of the child who was killed said to an interviewer in 1973:

(Brandt) explained to me that the Fuhrer had personally sent him, and that my son’s case interested the Fuhrer very, very much. The Fuhrer wanted to explore the problem of people who had no future – whose life was worthless ... From then on, we wouldn’t have to suffer from this terrible misfortune, because the Fuhrer had granted us the mercy killing of our son. Later, we could have other children, handsome and healthy, of whom the Reich could

be proud ... Germany had to be built and every bit of energy would be required. That's what Herr Brandt explained to me. He was a proud man – intelligent, very convincing. He was like a saviour to us – the man who could deliver us from a heavy burden. We thanked him and told him how grateful we were. (Cited in Lifton 1986, p. 115).

Other families and medical practitioners learned of the case and made similar appeals for euthanasia on compassionate grounds. And so the German Government sponsored euthanasia program commenced. The memorandum from Hitler authorising the program, entitled Aktion T4, was signed at the end of October 1939 with retrospective effect to September 1, the day Germany invaded Poland. It stated: "Reichsleiter Philip Bouhler and Karl Brandt M. D. are charged with the responsibility of enlarging the authority of certain physicians to be designated by name in such a manner that persons who, according to human judgement, are incurable can, upon a most careful diagnosis of their condition of sickness, be accorded a mercy death". (Hitler 1939, cited in Gallagher 1990, p. 46).

It is worth emphasising that Germany's doctors were never ordered to kill people. No legislation was ever enacted. They were merely enabled and encouraged to murder. The killing was always presented as a rational, socially constructive and scientifically-based process. The bureaucracy associated with the Aktion T-4 program, and the related children's euthanasia program, was particularly impressive. Quasi government corporations were established to facilitate the social cleansing – the General Patient Transport Company, the Foundation for the Care of Institutions in the Public Interest, and the Association of Sanatoriums and Nursing Homes looked after transportation, finances and administration of the Program respectively. Condolence Letter Departments was responsible for notifying families of a patient's death. Relatives were charged a fee for final medical treatment though without knowing its murderous purpose. Occasional administrative errors occurred. One family was advised twice that their handicapped son had died – of different causes – and received his ashes twice.

Bureaucrats were attracted to the work because of good conditions and career opportunities. The work was challenging, exciting, scientific and morally uplifting, as it would remove the stain on humanity and the financial burden on the community. The Directors of the killing programs liaised closely with senior members of the medical and legal professions. Academics and hospital administrators mostly embraced the Program and encouraged their students and staff to do the same. Various euphemisms were used to sanitise the process. For example, people were not killed but 'disinfected'. Official referral forms were used, policies and procedures were developed and implemented with penalties for non-adherence, assessments of patients were undertaken with the outward appearance of scientific precision, and medals – usually the Iron Cross Second Class – awarded to the most enthusiastic and efficient attendants.

The mercy killing facilities were designed and constructed with due regard for the sensitivities and sensibilities of the doctors, nurses and attendants who would actually lead the mostly unsuspecting victims to the death chambers. One such facility was described thus:

The Hadamar gas chamber was set up in the basement, in a room about ten by sixteen feet, with a ceiling eight feet high. The chamber was rigged up to look like a shower room with nozzles out of which – at the touch of a button – would flow carbon monoxide rather than water. About the perimeter of the room were ranged chairs and benches for the use of the patients. Some twenty to thirty patients could be accommodated comfortably. (Gallagher 1990, p. 14).

The 'final medical assistance' was carried out in accordance with regulations by a doctor, after the nurses and attendants led or carried the patients into the chamber and assisted them to undress. "When the chamber door was locked and sealed, it was he who pushed the button which caused the poisonous gas to pour through the shower nozzles. He would watch this through a peephole in the door" (Gallagher 1990, pp. 14–15). After twenty minutes or so the door was opened and those inside certified as dead by the doctor. Attendants, or sometimes other patients, then removed the bodies which were quickly cremated, the smoke from the crematorium chimneys drifting over the local townsfolk.

The doctors, bureaucrats and attendants were very proud of their work:

One day in midsummer 1941, the administrator came into the staff dining room at lunchtime to make an announcement. Today was the day they would cremate the ten-thousandth body to go into the Hadamar furnace. There would be a small ceremony and a staff party to commemorate the event. Accordingly, doctors, nurses, orderlies, even grounds attendants gathered in the lobby of the right wing in the evening. Beer and wine were served, and then all present filed downstairs to the crematorium in the basement. The room had been decorated, and the oven itself was bedecked with fresh flowers. On a gurney in front of the oven was the naked body of a dead man – the actual ten-thousandth victim. The body was adorned with flowers and small flags with the swastika emblem. Standing with his back to the oven door, Dr Brenner gave a short, inspirational talk about the importance of the work that was being done at Hadamar and his pride at being part of such a dedicated and hard-working team. With a nod from Brenner, the body was placed in a trough-like structure and shoved into the oven. (Gallagher 1990, p. 20).

In the late 1930's, before mixed reactions and public squeamishness threatened to interfere with the Program, open tours of Germany's institutions were not uncommon. There were many supportive citizens but one unimpressed visitor recounted:

After we had visited a number of other wards, the asylum director, who was called Pfanmuller, led us into a children's ward. The ward made a clean and cared for impression. In about fifteen beds there were as many children, all aged between about one and five years old. In this ward Pfanmuller explained his intentions at some length. I remember the following as a condensed account of the sense of what Pfanmuller had to say: 'As a National Socialist, these creatures (he meant the aforementioned children) naturally only represent to me a burden upon the healthy body of our nation. We don't kill (he may have used a more circumlocutory expression instead of the word 'kill') with poison, injections etc. , since that would only give the foreign press and certain gentlemen in Switzerland new hate propaganda material. No, as you see, our method is much simpler and more natural. ' With these words, and assisted by a nurse who worked in this ward, he pulled one of the children out of bed. As he displayed the child around like a dead hare, he pointed out, with a knowing look and a cynical grin, 'This one will last another two or three days'. The image of this fat, grinning man, with the whimpering skeleton in his fleshy hand, surrounded by other starving children, is still clear before my eyes. Furthermore, the murderer declared that they were not suddenly withdrawing food, but rather gradually reducing the rations. (Unknown c1930s, cited in Burleigh 1994, p. 45).

In 1943, Pfanmuller established two special Hungerhauser ('starvation houses') at Eglfing-Haar with the express purpose of causing death by carefully graduated starvation. He personally

processed up to 300 referrals for active mercy killing per day and, as each attracted a fee, became a wealthy man.

Although limited killing, particularly of children, continued until after the war, the Aktion T-4 Program officially ceased in 1941. Pockets of religious opposition and localised protest action by some families and communities had combined with original targets being reached. It is estimated that, of a pre-war population of 300,000 mental patients, 40,000 survived. Two hundred thousand died at the hands of the medical profession, 60,000 as a result of allied bombing and other factors. Many of those who ran the euthanasia facilities were promoted to Germany's broader racial extermination program. For example, Franz Stangl, erstwhile director of Schloss Hartheim Asylum became the commandant at Sobibor and later Treblinka. The professional skills and technology developed at the euthanasia centres were refined and streamlined and their success able to be measured as units of output in the ovens of Auschwitz and other extermination camps.

The German doctors, their assistants, families, bureaucrats and the population at large of sixty years ago, were not essentially different from other civilised and intelligent human beings in their attitudes toward people with disability. What they did was certainly different because it was done on a massive scale. But the beliefs that led to the slaughter, such as the perception of Dr Pfanmuller that he was dealing with 'human husks' and 'lumps of flesh', were held to a greater or lesser degree in Britain, France, the US, Australia and elsewhere.

Had war not broken out, one must wonder to what extent euthanasia in respect of the mentally afflicted may have infected other Western nations impressed by the achievements of their German cousins. Until 1945, there were many proponents of medicalised murder. Mercy killing lost overt favour within civilised nations not on moral grounds – communities did not suddenly adopt a new code of beliefs that valued the mentally deficient – but because of its association with Nazism and the image of piles of corpses photographed at the end of the war inside the likes of Bergen-Belsen. The world had simply seen enough mass killing.

A more altruistic phoenix began to emerge from the ashes of Europe. The millions of corpses and displaced persons that were the legacy of the Second World War called for a better world. In Scandinavia, Bank-Mikkelsen and Nirje linked the term Normalisation with the treatment of people with intellectual disability, and began to talk of the need to make institutions more homelike. Everywhere the voices of eugenicists were gradually silenced, though in all of us there niggles at least a little of their message still. The human psyche and prejudice are never far apart. Such forces combined and new initiatives appeared. Educational programs for the 'trainable mentally retarded' and 'crippled children' commenced or developed anew. Non-government, parent based, charitable service delivery organisations appeared from nowhere. Groups such as Camphill, and later L'Arche, became internationally renowned as they established communities in many countries. Science and social obligation met in an uneasy liaison. IQ testing became an even more popular professional pastime. Substantial advances in medicine aided in diagnosis and treatment of conditions that had previously mystified everybody. The creation or evolution of professions such as psychology, physiotherapy, occupational therapy, speech therapy, social work, psychiatric nursing and mental deficiency nursing occurred exponentially as a consequence. The retarded, as they became known, were especially targeted as subjects of scientific and professional interest, much as had the idiots of a hundred years before.

Most countries gradually abandoned their legislation and associated policies and practices

concerning sterilisation and restricted marriages. But while some new institutions were built, those long established were largely neglected. Overcrowding was endemic, some facilities accommodating over 5000 inmates. Through the 1950's, calls for reform increased and slowly began to be heeded. In 1961, the newly inaugurated President of the United States, John F. Kennedy, established the President's Panel on Mental Retardation. In his view, "... although we have made considerable progress in the treatment of physical handicaps, although we have attacked on a broad front the problems of mental illness, although we have made great strides in the battle against disease, we as a nation have too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected" (Kennedy 1961, cited in Scheerenberger 1983, p. 247).

In 1966, Fred Kaplan and Burton Blatt smuggled a camera into several North American institutions and subsequently published *Christmas in Purgatory*. The images were pure Bedlam, and representative of institutions elsewhere:

In another institution we saw a young man who was glaring at us through the opening in the door of his solitary cell, feces splattered around this opening. He, too, was being punished for breaking an institutional regulation. In this particular dormitory, we had a good opportunity to interview the attendant in charge. We asked him what he needed most in order to better supervise the residents and provide them with a more adequate program. The attendant's major request was for the addition of two more solitary confinement cells, to be built adjacent to the existing two cells that, we were told, were always occupied, around the clock, day in and day out ...

... In each of the dormitories for severely retarded residents there is what is euphemistically called a day room or recreation room. The odor in each of these rooms is overpowering. After a visit to a day room we had to send our clothes to the drycleaners to have the stench removed. The facilities often contribute to the horror. Floors are sometimes wooden and excretions are rubbed into the cracks leaving permanent stench. Most day rooms have a series of bleacher benches on which sit unclad residents, jammed together, without purposeful activity, communication, or any interaction. In each day room is an attendant or two, whose main function seems to be to 'stand around' and, on occasion, hose down the floor, 'driving' excretions into a sewer conveniently located in the centre of the room. (Blatt & Kaplan 1966, pp. 13, 22, 34).

In seven other North American states, similar conditions were revealed. In other countries, an increasingly sensationalist media, along with advocacy and public interest groups, found and reported abuse and neglect everywhere. Once ignored, the plight of the retarded enjoyed some popularity for a time.

By the 1970's, a New Order was emerging. The Disability Industry throughout North America and Europe was different. The dominance of the medical profession was waning. Educators and psychologists, especially those with a behaviourist or operant conditioning orientation, comprised a new elite. Community services began to replace institutions. Simplistic interpretations of Normalisation became the fashion and those not on the bandwagon came to be considered the enemy, rather than professional arrogance and systemic solutions as they should have been. The 'retarded' were now the 'intellectually handicapped', later to become 'people with intellectual disability'.

To live independently became the Holy Grail. Masses of functional assessments and training tools were developed, ostensibly to help people maximise their intellectual potential, though in fact to employ more professional staff on more technical tasks. Nobody became independent – fortunately, as ordinary people choose inter-dependence anyway – though many people with mental illness or disability became socially isolated, lonely, homeless public nuisances. Few professionals gave much thought to addressing people’s fundamental need to be loved, cared about and respected for their individual worth.

Was history about to repeat itself? Institutions and a variety of other less than favourable consequences were the legacy of the profound thoughts, best intentions and intense efforts of the professionals who followed Itard and Seguin. They heralded the New Order of the 1850’s. Might awful consequences flow from the advocacy and change agency of Bank-Mikkelsen, Nirje, and Wolfensberger of just over a century later as well? Would their warnings against creating the perfect community-based service system, which their work and theories spawned, be ignored as had those of Samuel Howe and Hervey Wilbur who jealously guarded their concept of an institution as a place of education, not of custody?

The emergence of the principle of Normalisation in Scandinavia in the 1950’s profoundly affected and improved the lives of people who had a disability from the 1970’s onwards. Although the first use of the term is attributed to Maria Montessori, Normalisation was carefully defined and popularised by Wolfensberger in the United States in the 1960’s and 1970’s and was later substantially re-worked and redeveloped. Wolfensberger theorised that vulnerable people, particularly those with disabilities, were forced to endure an endless cycle of societal ‘wounding’. The common threads of wounding in this sense were that individuals, in addition to having a physical or functional disability, were burdened with a variety of societally imposed negative experiences that ensured their status within a permanent social underclass.

The principles of Normalisation and Social Role Valorisation aimed to redress and even prevent this wounding process by “the enablement, establishment, enhancement, maintenance, and/or defense of valued social roles for people – particularly for those at value risk – by using, as much as possible culturally valued means” (Wolfensberger 1992, p. 32). Thus, where possible, valued characteristics might be made available, even bestowed upon people, in order to facilitate acceptance, respect and genuine liking by the rest of the community.

Much of the wounding that Wolfensberger described is insidious or its seriousness evolves over time as many different varieties of wounds have a compound effect. Rejection, for example, happens to everybody. Most people cope through other compensating factors such as family, friendships, a comfortable home, employment, reasonable income, hobbies and interests, and so on. Most people who have a disability experience rejection regularly, usually through subtle and even unconscious actions by family and service workers, plus different manifestations of all or many of the other wounds Wolfensberger described.

Normalisation, or its numerous misinterpretations, took the Disability Industry by storm in the 1970’s and 1980’s. Government policies, even legislation, reflected the noble ideal of returning people with disability to their communities. Attendance at PASS or PASSING Workshops (Program Analysis of Service Systems’ Implementation of Normalisation Goals) became professionally fashionable in some countries. The comprehensive community service system became the goal. Wolfensberger was something of a prophet. He and his disciples even foresaw and still bemoan the misinterpretation and misapplication of his theories. But these voices have

not prevented even this supremely altruistic and idealistic overarching social paradigm from creating community service systems that are as flawed, and sometimes very nearly as evil, as the institution dominated service systems that preceded them.

The experience of the last two thousand years, and especially the two hundred year history of the Disability Industry in Europe and North America, should be worth something in our struggle to grasp that there still is a fundamental wrongness in the way we think and act today. There are, hopefully, no Dr Pfanmullers among us anymore. But then he and his ilk were only riding the crest of a wave which, while it has subsided, continues to engulf people with disability by ensuring they are not viewed or treated as ordinary people. The wave may not rise as high again, though the technology that enables genetic engineering and cloning has a variety of as yet undetermined implications and applications. Mixed with increasing personal and national competitiveness, a global and voracious economy, and greater emphasis on individualism rather than notions of community, vulnerable people may become yet more vulnerable to harm and exclusion.

PART II: *The Australian Experience*, together with the Bibliography, will appear in the next issue of Interaction.

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These two Parts are selected extracts from the first three Chapters of Rob Westcott's book "*Lives Unrealised*". Book Reviews can be viewed at www.ncid.org.au/aiid.htm

Lives Unrealised **Clienthood and the Disability Industry**

by Rob Westcott

can be obtained from:

Australian Institute on Intellectual Disability

GPO Box 771

MAWSON ACT 2607

Tel: 02 6296 4400

Fax: 02 6296 4400

Email: ncid@ncid.org.au

Price: \$36 (incl. GST) + \$7.50 postage & handling

Proposed Accommodation Initiative for People with Disability

Committed About Securing Accommodation (CASA)

CASA is a West Australian based parent group with approximately 300 members established during the year 2001 for the specific purpose of lobbying both the State and Federal Governments on issues regarding accommodation support for people with disability.

The following initiative is proposed by CASA. By providing a plan that will eliminate and resolve the backlog in unmet need in accommodation support that presently exists not only in Western Australia but Australia wide, it offers hope for the future for parents of people with disability who have reached crisis point.

This proposal, taken from a parent's perspective, will hopefully initiate discussion, debate and input within the sector on an issue that urgently needs addressing by both State and Federal Governments.

Presently in Western Australia it is recognised that –

- a) a major problem exists with accommodation support for people with disability and is growing;
- b) parents have little faith in the current system;
- c) governments need to become more pro-active and engaging with parents and to include this issue as a major agenda item in future policies and budgets;
- d) a firm plan and commitment to resolve the current crisis be initiated;
- e) a plan be adopted to deal with the ongoing demand for accommodation support.

It is generally recognised through published data that in Western Australia approximately 300 families of people with disability are in crisis and in urgent need of full-time accommodation support.

The initiative outlined by CASA is a proposal to meet the existing backlog in unmet need and a way forward to deal with future need. The initiative proposes to tackle the crisis problem over a period of six years and at the same time deliver a responsible model that for the first time provides parents with hope and certainty.

The initiative is a great opportunity for the Government to enter into a partnership with parents and to resolve this issue once and for all. It involves a transitional approach whereby the 300 people in crisis will be offered at least some form of accommodation support within the first three years and, within six years, be guaranteed to receive full-time out-of-home accommodation support.

This initiative also needs to be improvised and implemented for future planning by the Government as a preventative measure for parents from reaching crisis. A way forward would be where, as soon as a person with a disability reaches a certain age, say 18 years of age, they are automatically offered at least one week per month plus four weeks per year accommodation support, from which they transitionally move to two weeks per month plus four weeks per year and finally receive full-time accommodation support within a specific period, say 10 years. So within 10 years, full-time accommodation support will be provided. Under the model, there would also be a mechanism that allows parents who fall into crisis to bypass the transitional steps of care and proceed immediately into full-time care for their son or daughter with a disability. However, as the purpose of this initiative is to act as a preventative measure for parents from falling into crisis, it is expected that the demand for immediate crisis care would be reduced.

CASA understands the trauma that parents face when their son or daughter with a disability moves into full-time accommodation support. Having your disabled son or daughter leave home is, without doubt, the most heart-wrenching time in parents' lives. It is also a huge move for the person with the disability, giving up a lifetime of security to face the unknown. This is difficult enough for any young person leaving home, many times more so for those who don't fully understand what is happening.

For this reason, every person making the move to a group home should have the option of being given a timeframe during which to make the transition. Time needs to be spent in the planning, working with parents and the proposed resident to prepare them for the move. Once the move is made, it should be made gradually with accommodation support increasing incrementally over future years until full-time accommodation has been achieved.

Even then, the move to full-time residence only takes place if, and when, both the family and resident are ready.

This detailed planning and transition period is perhaps the biggest single factor for parents and the person with a disability for a successful accommodation service. Maintaining strong links between the agency and their natural family should be treated as top priority.

Most new residents take time to settle into their new environment. But given time, love, compassion and consideration, they find comfort and confidence in their new-found independence, whilst maintaining strong family links.

The alternative is frightening. People left at home with ageing parents until the situation finally breaks down, and then suddenly thrown into an institutionalised option, without planning or lead-time, have tremendous problems.

With children happily settled into a new home, parents have every reason to feel proud that they have made the right move.

The initiative proposed by CASA provides parents a transitional approach of accommodation support as opposed to immediate full-time accommodation support.

One of the benefits of the transitional accommodation approach is that it helps to go some of the way of alleviating the grief and trauma that is normally experienced by parents of people with disability when moving from full-time home care to full-time out-of-home care.

The example detailed below shows an option where 50 people move forward each year into the next stage of care. Within three years, the 300 people in crisis will have been offered some

form of transitional care and, within six years, will have been offered full-time care.

The proposed accommodation initiative is a committed plan that provides family carers of people with disability in crisis with hope and, most of all, certainty for the future.

ACCOMMODATION INITIATIVE PROPOSAL

300 People requiring care

**Cumulative Total
receiving
Accommodation Support**

- | | |
|--|-------------------|
| <p>1) <u>YEAR ONE</u></p> <ul style="list-style-type: none"> • 50 people receive full-time accommodation support • 50 people receive 2 weeks per month for 11 months plus 4 consecutive weeks in a twelve-month term • 100 people receive 1 week per month for 11 months plus 4 consecutive weeks in a twelve-month term | <u>200</u> |
| <p>2) <u>YEAR TWO</u></p> <ul style="list-style-type: none"> • 50 people receive full-time accommodation support • 50 people receive 2 weeks per month for 11 months plus 4 consecutive weeks in a twelve-month term • 100 people receive 1 week per month for 11 months plus 4 consecutive weeks in a twelve-month term | <u>250</u> |
| <p>3) <u>YEAR THREE</u></p> <ul style="list-style-type: none"> • 50 people receive full-time accommodation support • 50 people receive 2 weeks per month for 11 months plus 4 consecutive weeks in a twelve-month term • 100 people receive 1 week per month for 11 months plus 4 consecutive weeks in a twelve-month term | <u>300</u> |
| <p>4) <u>YEAR FOUR</u></p> <ul style="list-style-type: none"> • 50 people receive full-time accommodation support • 50 people receive 2 weeks per month for 11 months plus 4 consecutive weeks in a twelve-month term • 50 people receive 1 week per month for 11 months plus 4 consecutive weeks in a twelve-month term | |
| <p>5) <u>YEAR FIVE</u></p> <ul style="list-style-type: none"> • 50 people receive full-time accommodation support • 50 people receive 2 weeks per month for 11 months plus 4 consecutive weeks in a twelve-month term | |
| <p>6) <u>YEAR SIX</u></p> <ul style="list-style-type: none"> • 50 people receive full-time accommodation support | |

The above proposal is a plan that shows real commitment and appeal to parents in crisis, and will restore faith in a system in which people currently have little confidence. The proposal needs to take into account other concerns and considerations of parents and agencies. However, it forms a basis of a plan to go forward and resolve the current crisis in accommodation.

The initiative proposed will provide a number of invaluable benefits to people with disability and families as follows: -

- a stepping stone to full-time accommodation where parents would prefer one or two weeks per month over a longer duration of time, as opposed to immediate full-time accommodation, thereby allowing a greater distribution of government resources;
- parents and their families the option to take a planned four week holiday per year which they presently are unable to do;
- a better quality of life for families;
- an opportunity for parents to recharge their batteries and care for their son or daughter on a transitional basis for a longer duration of time;
- a sensible process for parents and their son or daughter with a disability to adjust and familiarise to the out-of-home living environment when moving from full-time home care to full-time out-of-home care;
- a partnership of a share-cared management between the parents, agencies and DSC;
- for the first time, provide family carers with certainty and hope that presently does not exist; and
- act as a preventative measure for parents from reaching crisis.

If you wish to contact CASA, details are below:

Richard Diermajer
Tel: 08 9481 3322
Mobile: 0402 109 163

Carol Franklin
Tel: 08 9398 6329
Mobile 0438 167 766

WHO PAYS?

“Who pays for what” in accommodation services for people with intellectual disability

Jim Simpson

Impetus for the “Who Pays?” project

This project arose from concerns often expressed to the Western Sydney Intellectual Disability Support Group that residents of accommodation services were being expected to pay for more and more items that had traditionally been paid for by the service provider. There was a concern that, over the last twenty years, there had been a gradual and often quiet shift towards “user pays” so that residents had less and less money for discretionary spending.

Residents of intellectual disability supported accommodation usually have very small incomes. Most have the disability support pension and, in the past, this may not have been seen as a problem. People with intellectual disability were seen as only having very basic needs. These needs were met by the supported accommodation service and perhaps a congregate day program.

Fortunately, times have changed! A strong consensus of opinion says that people with intellectual disability are equal people with equal rights. They are entitled to varied and stimulating lives with a similar range of life activities as are enjoyed by other people. However, a varied and stimulating life can be expensive! Whilst legislation and government policy calls for this sort of life, achieving it for an individual is an ongoing challenge.

Providers of accommodation services are faced with this challenge – how to ensure a decent lifestyle for their residents, despite residents having meagre incomes and the service having tight funding. In some cases, this challenge may have been made all the greater by government funding being cut or not keeping up with escalating costs.

In response to these challenges, service providers and residents are constantly facing the question, “Who pays?”. Does the service provider or resident pay for a particular item? And, do residents pay individually or collectively through higher fortnightly charges out of their Centrelink payments?

Process of the project

And so the Support Group has carried out the *Who pays?* project. The project focused on the range of funded accommodation service types in New South Wales. Information was gathered from a variety of sources, including:

- Responses to a questionnaire from 40 people and organisations.
- Departmental policy and procedure documents and other relevant publications.

The project explored current and changing patterns in fees charged by accommodation services

and in who pays for particular items. The *Who Pays?* Report was released in early 2004.

The information collected

The report sets out in detail the information gathered in relation to different funded service types:

- Marsden Centre, Rydalmere Centre and Marsden Rehabilitation Centre (the three NSW governmental institutions in western Sydney formerly known as Metro West Residences)
- NSW government group homes
- Non-government institutions
- Non-government group homes
- Non-government accommodation support.

Particularly detailed information was available in relation to the former Metro West Residences. Over the last twenty years, there have been **both** increases in fortnightly fees (from two thirds to 75% of pension) **and** major shifts towards residents paying extra for items that were formerly covered by fortnightly fees – for example bedroom furniture, pharmaceutical items, haircuts and day activities. Residents are now paying considerable fees to private operators for day outings and holidays.

Marked variations in practice

The project found major variations in practice both within service types and between service types in relation to:

- Regular charges paid by residents to accommodation services.
- What residents get from the service without an additional charge.
- Whether the service or the resident pays for particular items.

These variations may arise from a wide range of factors including:

- The service's funding and other sources of income.
- Funding cuts.
- Varying support needs of residents.
- Astuteness of service managers in obtaining all available government assistance.
- Availability of goods and services without charge, for example day programs and professional services.
- The type of staff employed and the use of temporary staff. For example, nursing staff are paid more.
- Philosophy, policies and skills of service boards and managers.
- Access to, and quality of, advocacy.

There are variations in practice in relation to many items, such as:

- Who pays for toiletries.
- Transport costs – Does the service provide transport? Who pays transport costs?
- Insurance of residents' property – Is it insured? At whose cost?
- What items are specifically covered by the government funding agency.
- Whether staff of the accommodation service take residents on holidays and outings.
- Who pays workers' expenses?

Holidays and outings with private operators

At the NSW government institutions that were studied, there has been a marked shift towards using private operators for day outings and holidays.

There are legitimate philosophical arguments for residents going on holidays and outings with services different from their accommodation service. However, the Metro West experience shows that this approach can lead to these outings and holidays being very expensive - they are only available from a small number of unregulated private for profit operators and residents have to pay for the support needs associated with their disabilities, i.e. for paying support staff. Day outings cost about \$140 and a four day holiday costs as much as \$1,500 (or \$3,000 if a resident needs one-to-one support). People with intellectual disability are paying far more than other members of the community who visit the same place.

Metro Residences states that it looks at whether holidays are value for money and monitors the services provided by holiday companies. However, there needs to be a more formalised system of accountability and monitoring for private for profit operators. There is such a system in NSW for disability boarding houses but not for other private services.

User pays!

There appears to have been a major shift towards “user pays” over recent decades.

The shift to user pays is partly a reflection of a trend towards a broader range of life experiences and options being made available to people with intellectual disability. However, it can also be a way that a service deals with its budget difficulties. There are dangers that these two factors become blurred – a new practice may be justified as providing broader life experiences when it is really prompted by a service’s budget bottom line.

Sometimes, user pays is justified on the basis that it allows goods and services to be more personalised, for example in relation to bedroom furniture. However, service providers should be personalising their service provision anyway, so as to comply with Disability Services Acts.

Who pays for property damage?

The report found varying practices in relation to the circumstances where a resident is expected to pay for property that he or she has damaged. The Interagency Protocol between the NSW Department of Ageing, Disability and Home Care (DADHC) and the Office of the Protective Commissioner states best practice on this issue. Payment can only be requested if damage persists after a review of a behaviour program and a process of consultation leads to a consensus that the resident is “responsible” and will benefit from taking responsibility for the damage. Also, the resident must be able to afford to pay.

These rules acknowledge that property damage will often reflect an impoverished environment, boredom or other deficiencies in service provision rather than an intention to do something wrong.

The Interagency Protocols also acknowledge that a service should pay for damage to residents’ property where the damage results from the service not taking reasonable care to avoid foreseeable damage.

Equity and fairness

It is certainly unjust where residents' capacity to have a decent lifestyle is dependent on financial assistance from families or an unsustainable depletion of savings. These appear to be common situations.

As was noted in case studies in the report:

What is striking about each of these examples is that a fairly modest enhancement of the very basic lifestyle in a large institution is leading to individuals living well beyond their means.

A key factor is whether residents have access to a funded day program. It is unjust that a high proportion of residents of supported accommodation do not have this access.

There is a fundamental issue about what is fair in terms of how much money a resident has available for purely discretionary spending like a soft drink or movie ticket.

The need for parameters and transparency

There is much to be said for funding agencies placing some parameters around accommodation services in relation to their charges and what residents get for those charges. The current unregulated situation leaves a clear risk of unfair practices and exploitation.

Service providers also have a problematic conflict of interest if they are effectively deciding whether they or residents should pay for particular items.

However, the workability of regulation needs careful consideration. Each service has its own context and financial situation, influenced by various factors. And, as one parent said, having resisted fee increases by a service, he found residents paying individually for more and more items.

There should certainly be transparency and consultation with families and other advocates in relation to fees, what residents get for their fees and who pays for particular items. Funding agencies need to insist on transparency and consultation.

The Interagency Protocol between DADHC and the Office of the Protective Commissioner is a worthwhile initiative towards greater accountability. In NSW, the Protective Commissioner is the government agency that can be appointed by the Guardianship Tribunal to manage the finances of a person who is "incapable of managing his or her affairs". The Interagency Protocol spells out processes and parameters in relation to what a resident of DADHC supported accommodation can be expected to pay for. The Protocol includes:

- A process for consultation with the resident and family/advocate in relation to non-routine spending.
- Guidelines in relation to requests for a resident to pay for items such as bedroom furniture, items required for specialised needs, staffing costs on holidays and damage to property.

These sorts of guidelines should be part of good practice and not only apply when a formal

financial management order has been made. The formality, bureaucracy and intrusion of financial management should be avoided unless it is needed in a particular situation.

Funding responsibility of government

Funding agencies need to look at better systems for regulation and transparency of service providers around the issue of “Who pays?”. However, there is also a bigger issue about funding levels for disability services. If Government is really committed to a decent life for people with intellectual disability, it needs to fundamentally increase the funding for disability services.

Many of the problems outlined in the *Who Pays?* report can only be properly addressed by much better funding for the range of services and other supports that people with disability need. It is simply unjust when accommodation services shift costs onto poor residents for want of adequate funding from government. It is unjust that residents have to pay \$140 for a day outing or \$1,500 for a few days away.

**Copies of the *Who Pays?* Report
are available from:
Western Sydney Intellectual Disability Support Group
PO Box 249
Ermington NSW 1700
Telephone (02) 9334 0573
wsidsg@optusnet.com.au**

*** New look *Interaction* ***

The format for *Interaction* has changed. The layout has been made simpler and the cover will have the same design and colour from now on. These changes have been made to keep the costs of producing *Interaction* to a minimum.

The Australian Institute on Intellectual Disability and NCID have a strong commitment to ensuring that *Interaction* remains affordable for families and students. As such, there has been only one increase in price over the last 10 years, and you have our assurance that we will continue to endeavour to keep production costs low so that price increases in the future are kept to a minimum.

Ways in which you can help:

- Interaction does not take paid advertising for events and conferences, books and educational material, etc.
- Do you know of a company that may be able to assist with printing costs?
- We accept donations (which are tax deductible).
- **But, the biggest help that you can provide is to write articles about issues that impact on the lives of people with disability from the perspective of people with disability and/or their family.**



Australian Institute on Intellectual Disability

PO Box 771

Mawson ACT 2607

Ph: (02) 6296 4400

Fax: (02) 6296 4488

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