Reading 1.

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History of services

E Cocks and D Stehlik

LEARNING OBJECTIVES

After studying this chapter the reader should be able to:

- identify the key historical universal themes and issues in the treatment of people with disabilities and relate these themes to the Australian historical context
- understand the pivotal role of the early colonial heritage in Australian service development
- describe the influence of the parent and rights movements in providing a foundation for a view of people with disabilities as developing individuals who belong in the community
- comprehend the changing role of governments in service developments
- understand the key human service principles and ideologies that have emerged since World War II and their role in the development of services and the place of people with disabilities in modern society

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identify key trends in service provision for people with disabilities since World War II

consider the possible major future trends in service provision.

Introduction

AN ACCOUNT of the history of service provision is a necessary foundation to understanding the situation of people with disabilities in Australia. The manner in which society thought about, perceived and treated people with disabilities in the past has had an impact on modern society. In fact, thousands of people with disabilities in Australia are provided with services that were based on the thinking of centuries ago. Like many other groups, people with disabilities are vulnerable to ideas of the past. A knowledge of the history of services, then, may raise awareness and possibly prevent undesirable outcomes in the future.

This chapter begins with a brief account of the treatment of people with disabilities over the past 200 years and describes some of the major influential international developments. Five time periods are identified to describe development in Australian services. First, the period from the European foundation of Australia in 1788 to the close of World War II, a time characterised by the influence of our colonial origins and the focus on custodial care. Second, from 1945 to the mid 1960s, foundations were established for the reform of disability services with the development of the parent movement and involvement of the Commonwealth Government. Third, the period from the mid 1960s to the mid 1980s saw the implementation of major service reforms in Australia. These reforms were strongly influenced by new ways of thinking about disability that were connected with a number of powerful human service ideologies. The period from the mid 1980s to the present is characterised by an acceleration of service formalisation accompanied by greater government influence and increasing concern about the economic issues of service reform. Finally, we provide some concluding comments about the possible future developments in disability services.

Universal themes

This section will focus on two universal themes in the treatment of people with disabilities over the past 200 years. First, how has Western society thought about people with disabilities and second, how has service provision changed during this period?

The manner in which society thinks about people with disabilities strongly influences the way they are treated. The way people with disabilities are treated also influences the manner in which society thinks about them. This is a sort of self-fulfilling prophecy. If the predominant view is that people with disabilities are ill and diseased, they will be treated within service systems that function as hospitals. If the ordinary citizen sees people with disabilities cared for in medicalised services, the perception of sickness is reinforced. At the same time, people with disabilities are likely to internalise these experiences and think of themselves as sick. If people with disabilities are thought of as a menace—as indeed they have at various times throughout history—their treatment will reflect that belief and services will detain and punish them. If people with disabilities are viewed as human beings with potential for growth and development and as belonging with families and friends in their communities, then services are likely to be provided that will support related outcomes.

The social roles into which people with disabilities are cast ultimately shape personal and service outcomes. Wolfensberger (1975; 1992) describes a key set of historical roles for people with disabilities. These roles include being seen as non-human, a menace, an object of ridicule, an object of pity, a burden of charity, a child, a diseased organism and as dead or dying. They represent universal influences on the perception of disability and must be understood in order to comprehend history fully. They provide an insightful interpretive framework for considering historical and contemporary responses to people with disabilities. Different roles were more influential at various times in history, for example the 'menace' role influenced the treatment of people with disabilities from the late nineteenth century through to the mid twentieth century.

Historically, people with disabilities were regarded as being different from ordinary people and the nature of that difference was seen as undesirable. They were recognised and treated according to devalued characteristics—whether they be physical or mental. In sociology this is described in theories of social deviancy. Although these characteristics and roles differ from one historical period to another, and from one society to another (called *cultural relativity*), there have almost always been two universal outcomes for people with disabilities. The first is that they have been grouped with other people who are thought to share similar characteristics. It is thus very common throughout history for people with disabilities to be congregated 'with their own kind'. Groups included people with disabilities, as well as people accorded low social value, for example people with diseases such as leprosy, criminals and people with mental illness. When people are grouped together, it is common for some of the characteristics of one group to transfer to another. Therefore, by tracing the historical treatment of people with disabilities, we can identify different times in which they were grouped with other devalued people and thereby were assumed to have similar characteristics.

The second universal outcome for people with a disability who are accorded low social value is that they are segregated from others in society who have a higher social value. This segregation—a form of rejection—may range from being very subtle to being cruel and blatant.

Australia's convict and colonial origins served to accentuate juxtapositions by congregating people with impairments, 'lunatics' and convicts and segregating them through practices of confinement. In New South Wales prior to 1811 lunatics (including people with 'mental imbecility') were confined to the gaol at Parramatta. In 1811 Castle Hill was the first asylum established in Australia, intended by Governor Macquarie to be provided under a humane regime, but becoming overcrowded within months. In Western Australia from 1831 lunatics were placed in the Round House, which was Fremantle's first prison (Lewis 1988, pp 5–7). Prior to the Round House, the *Marquis of Anglesey*, a hulk of a merchant ship in Fremantle harbour, was used (Ellis 1984, p 4). Parallels with the British system here are clear. In Victoria in 1840 the first gaol was established as the Collins Street West Gaol. It was here that 'the first attempt was made to assist [sic] the Colony's lunatics' (Brothers 1962, p 11). Clearly, the penal nature of colonial Australia influenced the perception and treatment of people with disabilities.

Helping forms have changed dramatically over the past 2000 years. Wolfensberger and Thomas (1994) have detailed the historical origins of human services and described the early Christian era as one in which people lived in closely knit communities with personal service in one's own home being the common helping form. Around 300–400 AD. Christianity was adopted by various rulers as the official religion and forms of organisational helping emerged in churches, parishes and monasteries, overtaking voluntary helping forms. The period marks the beginning of a process by which helping became formalised, that is, occurring within formal organisational frameworks and being carried out by people assuming professional roles and receiving payment for what they do.

During the Middle Ages there were a number of occurrences that brought about the collapse of the welfare system. Plagues, climate changes, costly warfare and the debasement of currencies through imperialism and seeking precious metals contributed to a dramatic rise in pauperism. The subsequent increase in demand for help was aggravated by the decline of the monasteries during the Reformation and the development of a hardening of attitudes towards people in need. This was partly influenced by Calvinistic beliefs that perceived worldly success as a source of virtue and failure as linked with evil and divine punishment.

In the Middle Ages a number of measures were adopted in Western countries that were harmful to vulnerable people. There was a tremendous growth in confinement of poor and afflicted people, especially in leprosaria which had become vacant with the decline of leprosy (Foucault 1973). This contributed to the perception of disability as a disease that could be transmitted. Practices of rejection were common and included branding people as beggars and vagabonds; whipping and even execution; placing people on 'Ships of Fools' and casting them adrift; and transportation to penal colonies. Governments developed strategies to deal with the increasing numbers of needy people, well exemplified by the English Poor Laws and the workhouses which were called Bridewells. Finally, poor and afflicted people were grouped with criminals in a consolidation of institutions into the general hospital (the *Hôpital Generale* of Louis XIV) and their carers were given uniforms, arms and approval to implement punitive methods of treatment, such as stocks and pillories.

It is of great historical significance that many modern formal human services operate regimes that mirror military settings, for example in architectural features, the use of uniforms, badges of seniority (rank), disciplinary procedures, hierarchical structures and regulations. Judge (1987, pp 25–6) describes the regulations utilised at Kew Cottages, an institution for people with intellectual disabilities in Melbourne, where staff were titled 'warders'.

The late eighteenth and early nineteenth centuries, the time of the colonisation of Australia, is described as the Enlightenment period and was a critical time in the evolution of thinking about people with disabilities and other groups of vulnerable people. The Enlightenment period saw the adoption of science and rationality and the abandonment of superstition. It was not only physical science that was affected by the new ways of thinking—there were also significant political changes associated with revolution and the rise of modern political democracies. Forms of helping vulnerable people were influenced by the belief that disablements of people were in the domain of the body and were essentially a result of illness and disease. The so-called 'medical model' and all its attendant assumptions virtually redefined all forms of human need including, of course, physical and mental impairment. The nineteenth century was therefore marked by the dominance of medicalised treatment and service forms (Garton 1988). It also represented an acceleration of the formalisation of helping services, the growth of a commercial approach and the 'embedding' of people with disabilities—along with other groups—within formal service systems that were economically dependent on their 'clients'.

Methods of treatment during this period reflected the belief that disability and insanity were diseases. Common methods of treatment included many different forms of physical restraint; hippotherapy (horseriding); hydrotherapy (sometimes involving the complete immersion of the patient in iced water); use of various forms of apparatus that provided 'whirling therapy'; the use of electricity; and 'territion', a treatment based on the notion of a 'hair of the dog' cure that attempted to terrify and intimidate people into sanity (Judge 1987; Lewis 1988; Wolfensberger & Thomas 1994).

The Enlightenment period was also a period of great optimism about the developmental possibilities for people with disabilities. From the late eighteenth century there was an increased focus on the education of children with disabilities, for example in 1774 Johann Heinrich Pestalozzi established the first school for fifty 'regenerate beggar children' in Switzerland. Abbe de Eppe founded the first school for deaf children in Paris in 1760 and then for blind children in 1784. The story of Victor, *The Wild Boy of Aveyron* (Itard 1962) told how Itard, a French physician to a newly established institution for 'deaf-mutes', took in Victor, a 'feral child' who was captured in the woods of Aveyron in 1799. After two years of systematic instruction by Itard, Victor, considered to be 'an incurable idiot', was described in the following way:

> In place of the hideous creature that was brought to Paris, there was to be seen . . . an 'almost normal child who could not speak' but who lived as a human being; clean, affectionate, even able to read a few words and to understand much that was said to him (Itard 1962, p xii).

While not representing a cure, under kind and systematic instruction Victor's progress influenced educational practices to the present day. Seguin was Itard's pupil and he, in turn, influenced Maria Montessori. Montessori was responsible for very significant educational innovations that continue to be implemented. Montessori schools are located throughout the world.

A significant reform movement occurred during the early nineteenth century and was based on the notion of *moral treatment.* These activities were concerned with the humane reform of gaols and asylums and were also connected to the anti-slavery movement. Well-known historical figures, including William Wilberforce, Lord Shaftsbury, Jeremy Bentham and Edward Wakefield, were involved in these efforts (Scull 1979). Philippe Pinel in France and William Tuke (a quaker and founder of the York Retreat in England) were leaders in the reform of asylums. Moral treatment was based on assumptions quite different to those that emerged as mainstream within the medicalisation of lunacy (Wolfensberger & Thomas 1994). Moral treatment presumed that people would act rationally and that they should not be excluded from normal activities and environments. It supported family-like situations and promoted minimal use of medication. Most importantly, moral treatment emphasised kind treatment and opposed the use of restraint, providing empirical evidence to support that position. Nevertheless, by the middle of the nineteenth century, medical interests had firmly established lunacy as a disease and doctors and psychiatrists as the appropriate treatment professionals. This was supported by legislation that empowered the medical role (Garton 1988; Scull 1979).

As late as the second half of the nineteenth century, many residential schools were established in the United States, some of which were small and located in local communities, run by superintendents who attempted to create family-like environments (Kugel & Wolfensberger 1969; Wolfensberger 1975). However, by the end of the nineteenth century, the optimistic and kind attitudes had transformed into feelings of fear and rejection which were associated with the *eugenics movement.*

Adapting from the British model – 1788-1945

The early history of Australia's European settlement is one of segregation and congregation within a model of custodial care. The societal stresses of the Industrial Revolution in Great Britain resulted in the transportation of over 160 000 men, women and children in a period of eighty years between 1788 and 1868 (Hughes 1988). Transportation has been described as a process of 'social excretion' whereby a society systematically rids itself of unwanted, devalued classes of people (Wolfensberger & Thomas 1994). Australia has the dubious distinction of being the 'only modern affluent society to have started as an experimental—or more correctly, expedient—dumping ground for a social problem group' (Jones 1990, p 8). While Jones goes on to suggest that the 'convict system . . . has no apparent negative legacy' (p 8), we would argue that it is possible to compare the history of the development of the Australian welfare system—founded as it was on custodial care—to the British welfare state.

The *Poor Law Amendment Act 1834* heralded a time of change in the attitude of the British state to its poorest and most devalued citizens. As the only form of assistance, the Poor Law and its manifestation, the workhouse, was 'hated and dreaded' by the working classes (Robson 1976, p 20). The Act was a further response to the social upheavals of the industrialisation and urbanisation of nineteenth century Britain, as well as the dire Malthusian predictions of an under-resourced and over-populated future. From this period, the concept of the 'deserving' and 'undeserving' poor developed; a notion that recurs throughout subsequent years. In addition, the 'governance of the poor', through Boards of Governors and the administration of the workhouses, provided a system of the management of welfare and of the distribution of resources according to market forces—a concept which is still with us. The *Lunacy Act 1845* enabled the establishment of lunatic asylums across Great Britain and created a Commission which was responsible for all hospitals and asylums providing care to people with mental illness. Victorian Britain became:

> gripped with a kind of custodial fever and all kinds of people who were not originally classed as 'curable lunatics' found their way into the institutions. People suffering from epilepsy, mental handicap, chronic alcohol abuse and simple senile dementia, plus an assorted flotsam of 'social inadequates' who did not seem best catered for in the prison system (Murphy 1991, p 37).

Asylums, being a cost to the state, were seen as a better alternative than the workhouses, which were a cost to the local parish. Institutionalisation and custodial care became a hallmark of the welfare response. This was the background to the development of welfare services in colonial Australia. Australia's first major buildings were prisons and custodial care became centred on the prison and the workhouse or factory (Salt 1984).

The history of institutions and the history of services to people with disabilities are closely connected (Wolfensberger 1975). The construction of purpose-built institutions for people who were seen as 'feeble minded' began in the mid-nineteenth century in North America and Great Britain. In Victoria the *Lunacy Act 1867* incarcerated all 'mental deviants' in mental institutions (Bowman & Virtue 1993, p 188). In Great Britain the *Education Act 1870* and the introduction of a national elementary school system identified a number of 'children [who] were suffering from a variety of physical and/or mental problems' (Simmons 1978, p 387). The subsequent Royal Commission galvanised various charitable organisations into action and was 'one of the major factors leading to the reconceptualization of mental deficiency as a social rather than a private problem' (Simmons 1978, p 389).

Australia's first institution purpose-built for feeble minded children was the Children's Cottages at Kew in Melbourne, built in 1887 (Judge 1975, p 170). Initially, the segregation and congregation of people into institutions was seen as the ideal response to a 'cure' or an 'education model' of care where training could be undertaken to encourage a return to the community in a state of normalcy. Instead, 'institutions became more or less permanent places of segregation' (Kanner 1964, p 139) and the distinction between lunacy and feeble mindedness continued to be confused, for example the Claremont Hospital for the Insane in Perth, built in the early part of the twentieth century, catered for both (Ellis 1984).

By the turn of the century a shift in attitude to caring for people with disabilities had occurred and was to have profound long-term implications. Since the 1870s social commentators were predicting a dire future for the human race. The theories of Charles Darwin, Gregor Mendel and Thomas Malthus developed a pseudo-science which was taken very seriously. In 1883 Francis Galton introduced the term eugenics: 'the science which deals with all influences that improve the inborn qualities of a race' (Kanner 1964, p 128). As these ideas became more popular, a shift occurred from perceiving people with disabilities as essentially educable and trainable, to seeing them as a menace. The concept of eugenics became intertwined with ideals of 'Empire' and maintaining racial purity. The 'scale of evolution also reinforced existing prejudices and biases [and b]lack and other coloured peoples were ranked below the Anglo-Saxon, providing a convenient justification for slavery and imperialism' (Bacchi 1980, p 135). The eugenicists argued that the continued 'breeding' of mental and physical 'defectives' had profound long-term implications for the rest of humankind, for example in Kew Cottages 'blame was put on the parents and there was an increase in social stigma' (Bowman & Virtue 1993, p 189). Fitzpatrick (1988, p 45) wrote:

> The possibility of exercising rational control over the natural laws of evolution appealed to many people who believed they could recreate a blueprint for a new social order ... The political programme of eugenicists tended to emphasise meritocracy rather than democracy, for it eulogised a social world in which selection would take place according to medically defined 'fitness' and 'endowment'.

British influence on services continued well into the twentieth century. The British *Mental Deficiency Act 1913* was the outcome of many years of investigation and interest in the way social problems in Great Britain were perceived to be linked to phenomenon of the 'feeble minded'. The Royal Commission on the Care and Control of the Feeble Minded, established in 1904, was well aware of the findings of previous reports about the poor health status of young British men in earlier recruitment campaigns for the Boer War (Bacchi 1980, p 136). Many writers have argued that the primary focus of eugenicists and the social reformers were women (Bacchi 1980; Fitzpatrick 1988; Wolfensberger 1975). Two factors were reponsible for this theory: first, the agreement that mental deficiency was inherited and, second, that feeble minded women were more fecund than normal women. Simmons pointed out the 'near hysteria' in the discussions by the Commission about 'feeble minded' women:

> mentally deficient women were thought to lack the moral restraints concerning sexual intercourse possessed by normal women [it was considered that] they often became pregnant and brought large numbers of illegitimate and mentally deficient children into the world. Since feeble-minded women were found in workhouses, jails, etc. and since they often became pregnant in or out of the institutions, the rate payers were forced to pay for the costs of confinement, and often, for the subsequent upkeep of mother and children (1978, p 394).

Eugenics, racial supermacy, patriotism and the health of the nation became the driving social issues in Australia in the early decades of the twentieth century. By the 1920s sterilisation as a response to feeble mindedness was seen by many as a genuine solution. In 1929 there was strong lobbying in Great Britain for an amendment to the *Mental Deficiency Act 1913*, which would allow for compulsory sterilisation (Fitzpatrick 1988, p 146). In the United States sterilisation laws had been enacted in many states along eugenic and racist lines. In Australia, Western Australia and Victoria proposed bills along similar lines. The 1939 Victorian Bill stated its purpose as preventing 'defectives and retarded children from becoming a menace to the community because of their absolute dependence on the State or others' (Bowman & Virtue 1993, p 190). This form of social engineering had strong community and medical support, but was defeated largely because of economic factors (Fitzpatrick 1988). In Germany the medical and psychiatric profession effectively applied technology and bureaucracy to the 'euthanasia' of people with disabilities, the mentally ill, gypsies and others (Gallagher 1990).

Post World War II — 1945–mid 1960s

By the end of World War II, the attitude towards people with disabilities started to change. With the development of vaccines during the War, childhood diseases (such as diphtheria and scarlet fever) disappeared and the sanatoria devoted to people who had tuberculosis emptied. The medical profession in general and paediatricians in particular began searching for new patients. At the same time, there was a natural reaction against the excesses of war and the idea of incarceration of people, and parents began to seek alternative forms of support for their children who had intellectual disabilities. In Australia two other factors combined with these which led to a change in focus of services. The first, the return of many men from the War who needed physical rehabilitation to assist them to return to the workforce, resulted in the establishment of the Commonwealth Rehabilitation Service in 1948, the first step towards direct care by the Commonwealth Government. The second was the development of a strong family culture within the Australian ethos—women were encouraged to return home and have children to repopulate and re-establish the country. The concepts of maternal deprivation, child attachment and child development (influenced by the theories of John Bowlby and others) strengthened the argument and the ideology of 'care in the family'.

The ideology of care in the family took twenty-five years to become a mainstream ideology. In the meantime, parents who decided that institutionalisation was not the option for their children were seen as radical and in opposition to the status quo. In Western Australia parents grouped together for mutual support—they were 'ostracised in public places, [their] children were stared at and rejected and schoolchildren were most unkind' (Hunt 1989, p 7). The devopment of the Slow Learning Children's Group of Western Australia is one example of similar organisations across Australia, North America, Europe and Great Britain. With modest beginnings centred on the need to provide a form of education to their children, and later expanding to include employment and accommodation alternatives, the parents' movement became a major force for change in social policy and societal attitudes. Their strength of purpose came from mutual support and rejection of the social stigmas then associated with intellectual disability. The organisation grew quickly. By 1955 it was an 'incorporated organisation with a State Executive, an occupation centre, monthly magazine and pre-schools' (Hunt 1989, p 23).

The change in government attitude towards people with disabilities grew slowly during the 1950s and early 1960s. With the establishment of the Commonwealth Rehabilitation Services (CRS) in 1948, the Commonwealth Government undertook to provide education and training to returned servicemen with disabilities through the establishment of a number of major rehabilitation centres. In New South Wales and Victoria there were large rehabilitation centres and it was here that occupational therapy and physiotherapy services were developed and professionalised. The Chifley Labor Government planned to incorporate the delivery of services to all handicapped Australians—not just returned servicemen—through the CRS, but this did not occur until 1978, thirty years later. Prior to 1978 the CRS was restricted to those individuals who were in receipt of Commonwealth pensions or benefits.

In most states care to people with disabilities (other than returned servicemen) was the responsiblity of State Governments and it was during this time, partly as a response to the growing strength and commitment of the parent movement, that State Governments finally began to accept some responsibility for reform in this area. State Government services for people with disabilities were located within health departments, often specifically within mental health sub-departments or divisions. This both reflected and contributed to the confusion in the minds of professionals and citizens about whether or not disability was primarily a health issue. Until recently, even some educational services for children with disabilities were located within health departments and hospital-like service settings. The impact of the changes in social policy in Great Britain once again were felt in Australia. The British *Mental Health Act 1959* replaced the *Mental Deficiency Act 1913* and 'overnight' people 'became "voluntary" instead of "detained" inhabitants of their hospitals' (Shearer 1981, p 96). In Australia the changes were felt a little later, for example in Western Australia the *Mental Health Act 1962* 'superseded the *Lunacy Act 1903*, bringing terminology up to date and reducing the documentation needed for admission for treatment' (Ellis 1984, p 136). By the early 1960s some services, for example day hospitals, workshops and out-patient clinics, were being provided outside institutions. In addition, the training of staff caring for people with disabilities became more common. In most states direct-care staff were nursing trained either as psychiatric, mental retardation or mental deficiency nurses. In the early 1960s Western Australia introduced the first group of direct-care staff trained primarily in a developmental–educational model. They were first called training assistants and later, social trainers. The stage was finally being set for the de-medicalisation of disability.

Ideology and reform – mid 1960s-1984

The period following World War II was marked by economic buoyancy and a sense of optimism and hope, both of which contributed to the development of a more kindly attitude towards people with disabilities. With the additional influences of parent advocacy and increased government funding and involvement, the foundation was laid for change. This was a time of considerable reform of services underpinned by strong, coherent ideologies that were based on positive expectations for people with disabilities and supported by developing program technologies.

Four important developments occurred in the period from the mid 1960s to 1984. First, a number of very influential human service principles emerged. Second, the advocacy and rights movements began to directly influence service reforms. Third, program and service technologies, some new and others not so new, were applied. All three developments presented a strong and coherent challenge to the prevailing views of disability which supported the custodial and institutional approaches to services and which resulted in congregation and segregation of people with disabilities. The fourth development, service reform, occurred largely in response to these influences and resulted in expansion of non-government sector services, the movement of disability services out of health and mental health jurisdictions, deinstitutionalisation and community services development.

Influential human service principles

Normalisation and *social role valorisation* (SRV) have had an enormous impact on disability services in the Western world. The normalisation principle originated in Scandinavia in the 1960s through the influence of Karl Grunewald and Bengt Nirje in Sweden and Nils Bank-Mikkelsen in Denmark (Nirje 1992). The first written presentation of normalisation (in English) occurred in 1969 (Kugel & Wolfensberger 1969). The most recent Nirje definition of normalisation states:

> The normalisation principle means that you act right when making available to all persons with intellectual or other impairments or disabilities patterns of life and conditions of everyday living which are as close as possible to or indeed the same as the regular circumstances and ways of life of their communities (Nirje 1992, p 16).

Normalisation became a mainstay of policy, legislative and service developments in Scandinavia. There has been considerable development of the normalisation principle by Wolfensberger since the late 1960s (Wolfensberger 1972). He provided significant reconceptualisation of normalisation and suggested the use of the new term, social role valorisation (Wolfensberger 1983). Social role valorisation is defined as:

> [t]he enablement, establishment, enhancement, maintenance, and/or defence 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).

Although clearly emerging from the normalisation principle, SRV includes such significant additional development of the normalisation principle as to stand in its own right (Cocks 1989). Possibly the most important additional conceptualisation of SRV is the purpose to describe, explain and suggest strategies to counter the universal occurrence of social devaluation. Social role valorisation is therefore concerned with *any* group of people who experience social devaluation, not only people with intellectual or other disabilities. Wolfensberger developed SRV as a *meta theory* in the sense that he brought together seven themes—made up of bodies of knowledge that include concepts, theories and empirical data—to elucidate social devaluation (Wolfensberger 1992). Heller et al (1990) carried out a Delphi study with a panel of experts in special education to determine the top twenty-five nominated articles in the field of intellectual disability that had most impact on the field. Wolfensberger's book on normalisation, *The Principle of Normalization in Human Services* (1972), achieved first place and his article on reconceptualising normalisation to SRV, 'Social role valorization: A proposed new term for the principle of normalization' (1983), achieved seventeenth ranking.

The *development model* (or principle) addresses the fundamental human issue of, and need for, personal growth and the development of competencies. The principle asserts that if personal competencies are enhanced, there will be many benefits for people, including positive social value and status, and physical and material wellbeing. Being competent contributes to self-esteem—high levels of competency can compensate for a person's significant disadvantages, such as severe physical disability or limited material resources.

The assumptions that underpin the developmental model are intrinsically positive and, while important for all human beings, are particularly important for people with disabilities or elderly people. The developmental model is associated with a range of educational and developmental technologies (eg methods of systematic instruction, such as applied behaviour analysis and precision teaching). A combination of the assumptions underpinning the developmental model and learning technologies has proved to be very effective, especially with people with severe impairments.

The most comprehensive articulation of the developmental model occurs within SRV theory as described by Wolfensberger (1983). Wolfensberger asserts that developmental and competency outcomes are the most frequently stated objectives of human services, especially services for people with disabilities, and therefore services have a particular responsibility in this area. In this regard, the developmental model stipulates that services must be *relevant* to the needs of people being served, and must also be *potent* or focused, powerful and effective in addressing needs.

The principle of *least restrictive alternative* (LRA), sometimes also referred to as the use of *least restrictive means* or *least burdensome method*, stipulates that any procedures used within a human service for the benefit of service users should be the least intrusive on the lives of those service users. The principle of least restrictive alternative is underpinned by the assumption that using interventions that are more restrictive than necessary will limit human dignity and independence (Turnbull 1981).

The principle of least restrictive alternative has legal origins which date back to judicial rulings of the United States Supreme Court in the early nineteenth century. These judicial rulings attempted to limit the extent of state influence and control (Burgdorf 1980). In the area of human services, LRA has had enormous influence in the United States in promoting educational integration and deinstitutionalisation (Bruininks & Lakin 1985). In human services the complexity of the LRA principle is reflected in the dilemmas between wishing to avoid over-protective, restrictive interventions, and acknowledging and responding appropriately to a person's real needs for support. For example there is ongoing criticism of both educational mainstreaming and deinstitutionalisation because of occasions where vulnerable people—people with a developmental or psychiatric disability—have been 'dumped' with inadequate support (see Chapman 1988).

The *dignity of risk* (Perske 1972) is a corollary of LRA and the developmental model. Dignity of risk means that people must have a degree of challenge and risk in their lives in order for them to grow and develop. The dignity of risk is particularly relevant to people with disabilities who are likely to experience over-protection.

These five ideas or principles—normalisation, social role valorisation, the developmental model, least restrictive alternative and the dignity of risk—constitute a coherent and powerful ideology. They have had an incalculable impact on services for people with disabilities and other groups of disadvantaged people. Although they are complex and subject to much misunderstanding, particularly in implementation, the principles are evident in policy, legislative development and service provision in Australia since the early 1970s. A study of any contemporary piece of legislation, for example the *Commonwealth Disability Services Act 1986*, the various states' and territories' disability acts, adult guardianship legislation and policies of service organisations and funding agencies, will reveal their influence.

Rights and advocacy

The 1960s was a time of great prominence for the human rights movement, exemplified by the civil rights movement in the United States. In addition to the rights of Afro-Americans, there was concern for other minority and disadvantaged groups. The women's movement and the anti-poverty movement grew in strength. The parent movement in the disability field was another expression of the endeavour to promote the rights and welfare of a minority group. In 1968, following an international symposium on 'legislative aspects of mental retardation', the International League of Societies for Persons with Mental Handicap created the Declaration of the General and Specific Rights of the Mentally Retarded. This Declaration influenced the subsequent United Nations' Declaration on the Rights of Mentally Retarded Persons 1971 and the Declaration on the Rights of Disabled Persons 1975 (Nirje 1992, p 6).

The disability advocacy movement in Australia was influenced by the broader civil rights movement in the 1960s and also by the development of parent advocacy associated with the post-war parent movement (Cocks & Duffy 1993). In the United States Wolfensberger formulated an approach to advocacy he called *citizen advocacy* (Wolfensberger & Zauha 1973). Citizen advocacy programs subsequently developed in many Western countries, the first Australian programs being established in Western Australia and Victoria in the early 1980s. This response to advocacy for people with disabilities has resulted in a large number of citizen advocacy programs being established throughout Australia.

The rights movement also gathered pace in the late 1970s and early 1980s with anti-discrimination legislation being enacted in New South Wales in 1977 and the gradual inclusion of disability in various equal opportunity acts in other states. The concept of rights also became increasingly influential in service policies and practices during this period. During the 1980s legal rights bodies, such as the Redfern Legal Centre in New South Wales and Queensland Advocacy Incorporated that specialised in advocacy for people with disabilities, were established in most Australian states.

Self-advocacy, more accurately termed self-help, developed quickly in the 1970s and early 1980s with international groups such as People First and Disabled Persons International. The International Year of Disabled Persons in 1981 provided a boost to the development of self-help in Australia. State Governments established disability advisory bureaus, which provided direct access to government by people with disabilities, unfiltered by service providers. A number of state-based self-advocacy groups were established, for example Force Ten, later retitled Reinforce, was established in Victoria following a meeting of interested people with disabilities and supporters in 1980. Reinforce played a significant role in attempts at service reform in Victoria in the 1980s.

Program and service technologies

In the 1970s services were influenced by the development and application of a set of program technologies associated with applied behaviour analysis. This analysis was based on learning theory and the work of behaviourists such as B F Skinner. Australian university departments of psychology taught this material from the 1960s and a growing band of professionals applied the technologies to people with disabilities in programs and services. Applied behaviour analysis in various forms, including precision teaching, task analysis and token economies, became very common. Although this trend was criticised because it was seen as mechanistic and was often used to adjust people with disabilities to environments that were sometimes harmful and restrictive, these program technologies enabled many people with a disability to overcome limiting behaviours and to develop adaptive behaviours. Behavioural technologies also challenged assumptions that people with disabilities, particularly more severe disabilities, were ineducable.

The optimism and excitement of this period were reflected in the growth of early intervention services for infants with disabilities. The anti-poverty programs and the early education program Head Start in the United States in the 1960s stimulated evaluation and research in this area, exemplified by a learning program in Washington for infants with Down syndrome that achieved very good developmental outcomes for the children. Similar programs utilising behavioural technologies and working directly with families were established in Australia, including Macquarie University, Royal Melbourne Institute of Technology and the West Australian Division for the Intellectually Handicapped (Pieterse, Bochner & Bettison 1988).

Further service reform focusing on developmental outcomes occurred within accommodation services for people with disabilities in the form of community skills training and a movement away from large institutional settings into smaller hostel environments. With vocational services, the work of Marc Gold (Galloway & Lecours 1978) and others provided methods that enabled adults with severe disabilities and many years of deprived institutional living to carry out complex tasks that challenged the low expectations held by their custodial carers.

Service reform

The combined influence of post-war optimism, the parent movement, the development of strong, hopeful and coherent ideologies, the rights and advocacy movements and the development of effective program technologies provided a fertile environment for reform of custodial and institutional services.

We will discuss briefly the three major areas of attempted service reform that occurred in the latter part of this period: the Commonwealth, state and non-government service sectors. First, Commonwealth Government involvement grew in terms of policy development and funding support to the service sector. The Commonwealth Government enacted the *Handicapped Persons Assistance Act 1974*. This Act provided greater flexibility in funding different service types. In the area of accommodation, for example, rather than funding being restricted to nursing home accommodation (a service approach that reinforced many negative stereotypes of people with disabilities and overlooked their developmental needs) smaller, community-based hostel accommodation could be funded. The Act also defined a new vocational service type called activity therapy centres (ATCs). This was an attempt to acknowledge the developmental needs of people with disabilities who either could not gain entry to, or were inappropriately sitting idly in, sheltered workshops. Activity therapy centres allowed for the provision of developmental and educational activities in sheltered workshops. Although this service type was problematic, it did acknowledge developmental needs and the need to provide a wider range of options for adults with disabilities.

Second, in the late 1970s and early 1980s a number of states engaged in large programs of service reform. In New South Wales the Richmond Report (Richmond 1983) recommended closure of many large institutions for people with disabilities and people with mental illness and the development of extensive community-based services, particularly accommodation. In Victoria, following the Premier's Committee Report (Evans 1977), services for people with intellectual disabilities were separated from mental health services and a new organisation was established in 1981 called the Mental Retardation Division. Various significant reforms were instituted as a result, including the closure of St Nicholas Hospital in Carlton and the relocation of all the residents, most of whom had severe and multiple disabilities, into ordinary housing in local communities. This was the first large institution for people with disabilities to close in Australia and one of the first in the world. In Western Australia reforms of accommodation services included the closure of Swanbourne Hospital for people with disabilities in 1984, preceded by group home developments and the closure of hostels that had been established in the 1960s and 1970s. Service reform during this period was somewhat uneven across Australia, but some reform occurred in virtually every jurisdiction. Change was not without its opposition. Major challenges to the reforms came from a range of groups including unions, staff, political groups, local communities and family members of people with disabilities.

The third area of reform occurred with the development of the non-government service sector. This sector included organisations that had been established in the period following World War II. Across Australia there were hundreds of organisations that were established in the decade following 1948. These organisations were usually parent-inspired, focusing initially on education for their children and as their children grew older, developing accommodation and vocational services. Although many organisations remained relatively small and localised, particularly in the larger states, some grew to enormous size, serving hundreds of people with disabilities in many different kinds of services and employing large numbers of staff. By the late 1970s many of these organisations were facing difficulties associated with the changing needs of their clients and increasing numbers of people requiring services. By the early 1980s an accelerating development of new non-government sector service organisations occurred. This development intensified in the late 1980s and early 1990s in conjunction with legislative reform and a trend towards reducing government involvement in direct services.

Formalisation of services — post 1985

Involvement of the Commonwealth Government in disability policy through the 1960s and 1970s was restricted to the CRS and the provision of funds to non-government organisations through the *Handicapped Persons Assistance Act 1974*. The Hawke Labor Government was elected in 1983, based on a platform of social change. The new Minister for the Department of Community Services, Dr Don Grimes, built on the change in thinking towards normalisation and community-based services, as well as on the residual excitement generated by the International Year of Disabled Persons in 1981. The Handicapped Programs Review, the first of its kind in Australia, enabled people with disabilities to be heard for the first time. It was an exciting time; a real watershed in Australian human services. All this activity came together to create an environment in the disability field where a visionary approach to 'anything was possible' prevailed.

The New Directions Report was released in 1985. After the excitement of the Handicapped Programs Review and the consultations associated with it, the New Directions Report was favourably received (Commonwealth of Australia 1985). One of the major recommendations of the Report, on which the Hawke Government acted almost immediately, was to repeal the *Handicapped Persons Assistance Act 1974* and replace it with legislation 'based on the principle of service program development' (DCS&H 1989, p 2). In addition, it was recommended that the legislation include a statement of principles and objectives outlining the rights of people with disabilities. Unlike the United States, Australians do not enjoy a Bill of Rights—our system is based on the British model of common law and the Westminster System of government. However, the principles and objectives of the *Disability Services Act 1986*, which were gazetted in June 1987, provided for the first time recognition of 'personal aspirations, realisation of potential and the enhancement of independence and self esteem' (Trowbridge 1993, p 50). They also incorporated important aspects of normalisation, the developmental model, LRA and the dignity of risk. Chapter 2 provides a detailed discussion of the principles and objectives of the *Disability Services Act 1986*.

The transition from institutional-to community-based services became a major purpose of the *Disability Services Act 1986* and the policies surrounding it. The legislation also supported the concept of 'consumer outcomes' and reinforced the assumption that the major purpose of services was the benefit received by people with disabilities. Funding was meant to reflect this as the *priority* rather than the *maintenance* of service organisations. This ideology shaped much of the thrust of policy and practice and was perceived by some services to be flawed and as an attack on established organisations. The Commonwealth Government began the implementation process by closing down its rehabilitation centres across Australia and developing community-based rehabilitation units. The first rehabiliation centre to be closed was Coonac in Victoria and the others quickly followed.

During the period 1983–1986, when Don Grimes was Minister for the Department of Community Services, the Commonwealth Government was convinced of the rightness of its policies and the determination for change was paramount. By taking the lead in this way, the Commonwealth Government faced criticism which claimed that such change was undertaken too soon, was too centrally controlled and was without sufficient thought for the consquences. For many parents and non-government organisations, the change to a policy of community integration based on individual needs was long overdue and extremely welcome. For many others, a fear of the possible abandonment of what were perceived to be safe and secure environments, such as sheltered workshops, became a source of concern. The Commonwealth Government was the major source of funds for change and the *Disability Services Act 1986* identified a five-year plan for development, ending in 1992.

By 1988 a number of new services, based on a community, integration and individual focus, had been developed. There appeared to be an impetus for change, but there was also a more coherent resistance. There had been a change of Ministers, the Departments of Community Services and Health had been integrated, and many of the Canberra bureaucrats who had been the primary force behind the changes had moved on. In a speech to the Australian Council for Rehabilitation of the Disabled (ACROD) Convention in November 1988, the then Minister of Community Services and Health, Senator Neal Blewett, outlined this resistance and the government's continued commitment to change:

> let me say that I am appalled by the tactics of some of our opponents who have shown themselves willing to do or say almost anything to frustrate the smooth implementation of the legislation and the new directions it enables us to follow. While it is forgivable for people whose fear is born out of ignorance to misrepresent our motivation and actions, it is totally unacceptable for people with vested interests—be they politicians or organisations—to frighten parents with deliberate misinformation designed to panic them into opposition of anything associated with the Federal Government, anything associated with change, anything leading to the positive outcomes made possible by the *Disability Services Act* (1988 p 5).

Despite the resistance, there were some major undertakings during this period. In Western Australia the last residents of the old Claremont Hospital were transferred to community-based residences and in 1985 the Authority for Intellectually Handicapped Persons was created. In Victoria a powerful report by community visitors about Caloola which stated that 'the waste of human lives at Caloola is immoral. The Centre cannot be salvaged' (Bowman & Virtue 1993, p 195) led to a State Plan for the Development of Intellectual Disability Services 1989–1992 released in 1989. Many organisations were developing or redeveloping services using the principles and objectives of the *Disability Services Act 1986* and the financial incentives offered by the Commonwealth Government.

As each reincarnation of the original Department of Community Services appeared (in the decade from 1983 the Department embarked on five major reorganisations) the impetus for change lessened. The conviction held by many people that this was the right direction became more influenced by pragmatic concerns and pressure to maintain the status quo. The conflict regarding sheltered workshops and their continued existence is an ideal case study. The importance of work was undermined by the congregation and segregation of many people with disabilities in places where they undertook activities that were largely devaluing (such as recycling old clothes, making shrouds etc). In some workshops such work was actually non-work—the items made were dismantled at the end of the day and the 'workers' continued to make the same things over again. There was positive response from many organisations that saw the potential offered by the *Disability Services Act 1986* and grasped the opportunity it represented. However, for many parents, particularly those who had struggled through the 1950s and 1960s to develop services for their children when the community had rejected them, the possible closure of workshops posed a threat to security and stability. Sheltered workshops became the pivot around which the Act and its policies became diluted and subsequently changed. In 1994 the Minister responsible for the restructured Department of Human Services and Health, Dr Carmen Lawrence, announced that sheltered workshops would not be closed.

During the 1980s there was considerable reorganisation of State Government disability services. In almost all states disability services were removed from health or mental health bureaucracies and shifted to welfare bureaucracies. Rationales for these changes are not altogether clear, but ostensibly it was presented in some states as an appropriate move because disability was not a health issue. The question was unanswered as to whether it is primarily a welfare issue. In some states, disability-specific legislation was enacted. The Victorian *Disability Services Act 1986* was enacted to take responsibility for organisational changes. Western Australia enacted the *Authority for Intellectually Handicapped Persons Act 1985* that established the only statutory organisation for disability and was later replaced by the *Disability Services Act 1993*, which established an independent Disability Services Commission. The 1980s was also a time during which traditional professionals and practitioners appeared to lose influence in services both as a result of the increasingly prescriptive role of the Commonwealth Government in determining the shape of services, and in the growing bureaucratisation of services that saw professional managers, who did not necessarily have a background in the culture of the disability field, assume key roles in service provision.

By the end of the 1980s the possibilities and excitement of the earlier years had turned into a pragmatic and managerial approach encapsulated in the term *economic rationalism*. The concept of 'value for money' and 'efficiency and effectiveness' became the guiding principles. Non-government organisations were encouraged to become businessess, to restructure themselves along managerial lines, to employ management experts and to develop an approach where profit, if not actually sought, became a motivating factor. The Commonwealth Government turned its energies into developing standards, quality of life indicators and measurements by which organisations had to be judged in their service delivery. As the five-year transition period drew to a close, the Commonwealth Government commenced negotiations with State Governments for its withdrawal from the funding of some services. These negotiations, called the Commonwealth/State Disability Agreements (CSDA), transferred the bulk of monies and responsibilities to State Governments for all services except employment and advocacy. In return, all State Governments had to establish their own disability services legislation which incorporated the principles and objectives of the Commonwealth *Disability Services Act 1986*. By the end of 1994 all states had effected their transition and are presently grappling with the implications of increased responsibility for services in an environment of a significant backlog of demand (for accommodation services in particular). The responses from State Governments have varied—from Victoria, where the managerial approach has been economically driven, to Western Australia, where an attempt at consultation and a slower process of assimilation of services is underway. In addition, some of the consequences of poor policy and decision making are becoming obvious as vulnerable people with disabilities struggle to survive in a community with limited support. Those who do have a home are better off, but this creates its own problems as families attempt to manage alone (Stehlik 1993).

Summary

Service to people with disabilities is part of the broader picture of societal response to all groups of people who are accorded relatively low social value. Following the early reliance on informal helping and personal service, people with disabilities received services in more formal ways. In the Middle Ages this occurred in the context of the churches until their decline, and the rise in numbers of people in need overwhelmed this form of service. The Middle Ages were also characterised by confinement of people with disabilities—along with other groups of socially undesired people—in large institutions. This was also the period of early social policy development—the state's efforts to deal with its social problems—and the use of laws to control and punish these groups. The Enlightenment period, about the time of the European settlement of Australia, introduced materialistic science and the ascendancy of the disease model of disability. This was accompanied by the development of specialised institutions and the dominance of the medical professions in care and treatment. This characterises Australian service development in the nineteenth century and first half of the twentieth century. The convict and colonial origins of Australian settlement contributed to this. The post-World War II period can be marked as the beginning of the remarkable growth of modern formal human services, associated with a great reliance on service and program technologies, including a range of new legislation. The more recent period over the past decade can be characterised as a time of economic and managerial rationalism, developed to a level of sophistication and complexity that could not have been predicted even twenty-five years ago. In summary, in this century we have moved from a custodial and medical model of services, through a time when positive developmental ideologies held sway, to a bureaucratic model of services.

We live in a modernistic culture that tends to deny and underestimate the importance of history. Yet the manner in which services for people with disabilities are provided is greatly influenced and shaped by history. Modern formal human services have become highly formalised and professionalised and rely on technology. This technology is not so much the machine technology of an industrial society, but more the technology associated with a post-industrial society. This is manifest in increasing levels of bureaucracy, regulation and management. Service providers in the late twentieth century operate in environments that are complex and demanding and where, arguably, it is increasingly difficult to determine the true purpose of human services. McKnight (1985) writes of modern society as a 'serviced society' and comments:

> Whenever hierarchical systems become more powerful than the community, we see the flow of authority, resources, skills, dollars, legitimacy, and capacity away from communities to service systems. In fact, institutional systems grow at the expense of communities.

In keeping with the broader development of post-technological Western society, this move towards formalisation has accelerated since World War II. However, its origins can be traced back to the time when organisational forms of personal helping and service overtook the place of informal help many centuries ago.

A knowledge of history shows that human services have always been multifaceted and served many purposes. They have operated to protect and to serve vulnerable people, to protect and to serve society and to provide very significant economic benefits. These purposes are usually in conflict. The resulting tensions are considered to be intrinsic in that they are a part of modern human services that cannot be denied. Modern human services, however, are surrounded by a new managerial rhetoric that is confusing. Modern human service language may also be obscuring the reality of the lives of people with disabilities. The language of efficient service delivery does not necessarily reflect the human element. The rejection and maltreatment of people with disabilities, along with many other groups of devalued people, are seen more easily in the historical context. The physical branding of people, their placement on Ships of Fools, their incarceration in large, dehumanising institutions and their actual destruction, is unequivocally clear in its intent. Has modern society overcome the rejection of some groups of people through congregation, segregation and abuse, or are these universal themes still present but in disguise?

It is apparent that ideology—the beliefs and assumptions held about people and their place in society—shapes the social response to disability. Human services have always proved to be malleable and successful in delivering what society demands. At various times in history services have provided control, incarceration, punishment and destruction. This should not be surprising since services are a product of the surrounding culture. Services have also managed to be supportive and helpful, and to provide kindly treatment. How should we characterise modern services on this dimension?

Finally, the philosopher Habermas (1989) has made some penetrating analyses of modern formal human services and posed a major conundrum. He raises the fundamental question of *means* and *ends* and asks: If our purpose is to liberate, empower and develop individual human beings, can this be achieved within a welfare and service framework that uses means that are essentially formal and controlling?

REVIEW QUESTIONS

1. Describe the key recurring themes in the perception and treatment of people with disabilities in Western society. How have these themes manifested themselves at different times in history?
2. What influence did Australia's convict and colonial origins have on service development for people with disabilities?
3. Identify and describe the major factors in the post World War II period that underpinned the move away from custodial care to more developmental outcomes in services for people with disabilities.
4. Outline the positive human service principles that emerged in the 1960s and 1970s and describe the key assumptions on which they were based.
5. Compare and contrast the roles of the Commonwealth Government and State Governments in services since the 1940s.
6. Describe the roles of the parent movement and the non-government service sector in service developments.

ESSAY QUESTIONS

1. What does the term *juxtaposition* mean? How has it occurred in the treatment of people with disabilities and what influence has it had on their lives?
2. What rationales have been used to congregate and segregate people with disabilities? What rationales have been used to engage in service reforms around deinstitutionalisation and 'mainstreaming?
3. Consider the various purposes of services for people with disabilities. Which of these purposes are most influential in modern society? What are the consequences for people with disabilities?

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