

**PARALLELS BETWEEN APARTHEID AND
INTELLECTUAL DISABILITY POLICY AND PRACTICE:
IMPLICATIONS FOR CITIZENS AND SERVICES.**

**Robert L Jackson
Edith Cowan University
Perth, Western Australia**

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ABSTRACT

Apartheid as a social policy has been universally condemned. However, an analysis of policy and practice in the field of intellectual disability shows many disturbing parallels with apartheid. In this paper, current and past services for people with an intellectual disability are compared to apartheid as a theory and as practiced. Some important similarities and differences are highlighted, particularly the fact that apartheid is explicit whereas the treatment of people with an intellectual disability is often directly at variance with statements of policy and annual reports. The physical environment of services, the activities undertaken, the grouping of people and the language used indicate a systemic rejection of people with an intellectual disability while the rhetoric indicates care and integration. It is argued that if the proposed parallels with apartheid are real, many issues at both a moral and strategic level are critical for services and individual citizens.

INTRODUCTION

On the 27th April 1994 the world witnessed an event as significant as the breakup of the Soviet Union and the demolition of the Berlin wall. This was the official date of the dismantling of the policy of apartheid in South Africa. For many, if not most of the citizens of the world, it was a time of shared joy with the people of South Africa who had been oppressed for generations.

It is my contention in this paper however that while the policy of apartheid is officially at an end in South Africa, the treatment of people with a disability in our society and the nature of the services they receive show striking parallels with apartheid policy and practice. Moreover, there is little movement to end this system, and in fact there is a widespread support in our society for the current treatment of people with a disability, for its continuance, and for its extension.

At the outset I should state that the examples that I use are not universal and there are many dedicated individuals and positive services actively working to reverse many of the problems raised. It also needs to be stated that there is no implication that people in society or services are evil and intend to harm people with a disability. On the contrary, the majority of people working in services are committed, caring individuals with a strong set of personal values. However, history teaches us that good intentions and personal morality are not enough. The nuns and priests who ran missions were not evil people - quite the contrary. Unfortunately this did not stop them doing great damage and destroying peoples' lives and cultures. The whole society supported them too. It is only with the benefit of hindsight that the implications of the mission policies have become apparent.

I should also state that the ideas in this paper are only attributable to me, although many of the ideas are drawn from a wide variety of sources - most notably Professor Wolfensberger and John McKnight.

HISTORICAL BACKGROUND

Apartheid (pronounced apart-hate) means “apart-ness”, the state of being apart, “separateness” or “separation”, and in the South African context means racial distinction (Bunting, 1971) . The public face of the policy was one of separate development, based on a belief that God had made races different so they should lead separate lives.

While oppression of black people had been present since European involvement in the 17th Century, the first mention of apartheid did not appear until 1943, and it was not until the 1948 elections that it was used by the National Party in South Africa to preserve “the safety of the white race and Christian civilisation” (Bunting, 1971) . The man considered to be the “father” of apartheid, Dr Verwoerd, spelt out the rationale for apartheid clearly in 1963:

Reduced to its simplest form the problem is nothing else than this: we want to keep South Africa white...Keeping it white can only mean one thing, namely white domination, not “leadership”, not “guidance”, but “control”, “supremacy.” If we are agreed that it is a desire of the people that the white man should be able to continue to protect himself by retaining white domination, we say that it can be achieved by separate development.
quoted by (Choncho, 1987, p106) .

Similar history and attitudes can be seen in the area of intellectual disability. While the early 19th century had seen several positive developments, by the end of that century “services” consisted of huge segregated institutions and workhouses, where the inmates were expected to work to earn their keep to minimise the cost to the government (Wolfensberger, 1975) . Terman, who brought the Binet intelligence test to America had views about intellectual disability not unlike those of Verwoerd above in relation to black South Africans:

“...only recently have we begun to recognise how serious a menace it is to the social, economic and moral welfare of the state ... It is responsible for the majority of cases of chronic and semi-chronic pauperism.”

... the feeble minded continue to multiply ... organised charities ... often contribute to the survival of individuals who would otherwise not be able to live and reproduce..."

If we would preserve our state for a class of people worthy to possess it, we must prevent, as far as possible, the propagation of mental degenerates ... curtailing the increasing spawn of degeneracy."

Terman, 1917. (Terman, 1917 p165)

There was further deterioration in the social conditions for people with an intellectual disability in the early 20th century with the growth in the eugenics movement. This culminated in the death of at least a quarter of a million people with disabilities under the Nazi regime in Germany (Gallagher, 1990) .

These days one rarely sees blatant expression of an oppressive position by a powerful person. Annual reports talk of noble human values while the services may be little different to those in Terman's time. In South Africa Premier Vorster (successor to the assassinated Verwoerd) assured us:

"... the policy of separate development is not a policy which rests upon jealousy, fear or hatred. It is not the denial of the human dignity of anyone, nor is it so intended (Bunting, 1971, p26) .

With apartheid, no one is taken in by such language. We learned to watch what they did, not what they said. This is a lesson yet to be learned for services to people with a disability.

PARALLELS BETWEEN APARTHEID AND DISABILITY SERVICES

The horror of apartheid in South Africa has been well documented (Anti-Apartheid Movement, 1974; Brookes, 1968; Clark, 1987; International Defence Aid Fund, 1972; La Guma, 1971; Skuy & Partington, 1990) . In the field of disability, Wolfensberger has been describing similar conditions for people with a disability for over two

decades (Wolfensberger, 1972; Wolfensberger, 1975; Wolfensberger, 1983; Wolfensberger, 1991b) . In 1983 he published an evaluation instrument, PASSING, together with Susan Thomas (Wolfensberger & Thomas, 1983) . This instrument gave a methodology for evaluating services along a range of dimensions related to the extent to which they contributed to reversing or extending devaluation and segregation. In a study covering the evaluations of hundreds of services using this instrument, it was found that the great majority of services did in fact contribute to the segregation and separate development of people devalued by society (Flynn, LaPointe, Wolfensberger, & Thomas, 1991) .

The following analysis draws on this literature as well as widely shared knowledge and experiences of services to point out parallels between the policy and practices of apartheid and common practices in human services for people with a disability.

Physical Rejection

In both the apartheid system and disability services, there are two major means of physical rejection - exclusion and segregation. Exclusion is the process of not allowing people to experience certain parts of the valued culture. This is most clear in areas such as education, where it is legal to exclude people from participation in valued schools. It can be seen in architecture, where people from the devalued group are excluded either by signs under apartheid, or by steps and other physical barriers for people with a disability.

Under apartheid, physical segregation was effectively universal. People were forced to live in squalid homelands or townships such as Soweto, forbidden to live in white areas and had to endure extremely poor housing and services. For people with a disability, the parallel is striking. To live outside the family home, most services have traditionally been in segregated hostels, villages or institutions. It is debatable whether the “reform” of group homes addresses the fundamental issue of having to be segregated and congregated with “their own kind” in order to receive basic living accommodation. Services are very rare that refuse to segregate and congregate people with a disability.

Numerous reports have been published on the atrocious and sub-human conditions experienced by people in these services, but the reality is that thousands of people with a disability still live in these conditions, and large congregated services are still being built where many generations of people will live out their lives apart from the valued community.

While anti-discrimination laws have had some impact, there are still regulations in local and state governments that restrict where and how people with a disability can live. For example, shared accommodation for people with a disability can be classed as an institution with community members able to object.

Under both apartheid and disability services, there are restrictions on time in the society, either by curfews under apartheid or institutional restrictions on outings, 'door lock times' or even times for lights to be out at night. Under both systems there is segregated sport and recreation. For people with a disability there is even a segregated Olympics, although they are not allowed to use the Olympic symbols. It is interesting to contemplate that while allowances are made in the Olympics for different sexes and different weight categories, allowances on dimensions such as disability are strongly resisted.

The segregation experienced under apartheid and disability services is widespread in the areas of work and education. As these are such major life areas they will be discussed separately below.

Social Rejection

Social rejection could be seen as being outside of the 'system' and refer more to how the general society treats a person or group. However, the system in both apartheid and disability services can, and does, carry out policies that increase the likelihood that such social rejection will occur. The primary way that this is done is through classification. Under apartheid, people were classified on the basis of skin colour as black, white or coloured. In intellectual disability the classification is on the basis of extent (or even genetic origin) of disability. Indeed large numbers of highly trained

professionals are employed primarily on this task and thousands of words are published each year in professional journals on how to refine this process.

Once a person has been classified as 'right' for the service, specific processes of social rejection come into play. Within service settings it is very common to have separate meal areas and toilets for staff, rules about "off limits" areas such as staff rooms, special privileges for staff not available to the people in the institution, different dress and status images for staff and clients, and access restricted to more valued jobs. This is a direct parallel with the apartheid system where such social distinctions were also institutionalised.

In both apartheid and disability services, there is a profound degradation of status for the people. This degradation of status is transmitted through a number of media (Wolfensberger, 1991a; Wolfensberger & Thomas, 1983) :

Physical environment

This can be either through location or physical attributes of a service. If a service is located far from other human beings, in a devalued area such as next to a rubbish tip, or near other services to devalued people, an image is associated with the group that is less than positive. Similar images are conveyed by the townships and homelands in South Africa. If the external attributes of a service are high walls, barbed wire, squalor, or other negative images then this aids social rejection. Similarly, internal characteristics of buildings can transmit images of difference, inferiority, dangerous or childlike.

Activities

If the activities undertaken by a group are things such as removing the garbage or recycling the waste of valued society then social rejection is more likely. Such examples are prevalent under both apartheid and disability services. Restriction of work to a limited number of occupations such as horticulture, cleaning and food preparation can put a clear 'class' stamp on people. If

curfews or time restrictions are imposed on a group then the images transmitted make rejection more likely.

Grouping

To place people together on the basis of a devalued characteristic is to magnify and reinforce that characteristic. It is in effect saying that the shared characteristic is their most important characteristic - more important than the aspects that they share with other people such as humanity, skills or talents. This is possibly the most powerful way of ensuring rejection of people, and it is also the most common practice in both apartheid and disability service. It also ensures that the models that people imitate have the same characteristics so differences to others are further highlighted.

Language

In South Africa, demeaning terms such as “boy” and “Kaffir” are widespread. Television images of black people portray them as a potential threat and in other negative ways. In disability service, major media campaigns are conducted for fundraising that portray people as childlike, pitiful, sick and incompetent. The press uses similar imagery in articles on people with a disability (Byrd & Elliott, 1988; Jackson, 1991) . For both black people and people with a disability, the imagery is associating the group with stereotyped roles that are devalued by society. Valued people avoid being associated with such roles.

Miscellaneous images

In South Africa, the name of laws such as the “Immorality Act” and Government programs relating to “Natives” can contribute to negative images and the devaluation of people. In intellectual disability, service names such as “mentally incurable”, funding associated with (ill) health, and logos that stress the negatively viewed characteristics of the people are some example of other images that can cause a degradation of status.

Human Relationships

One of the most inhuman aspects of apartheid was the way that families were split up so that one family member could get work.

Single men's hostels were set up in the townships, but the men's wives and children were forced to live in the homelands. This commonly meant that families did not see their father for months. This practice is directly reflected in disability service. Often the only way that a person can get a service is to move out of the family home into an accommodation service which may be many miles away. Families are faced with the choice of moving their family home to be near to their offspring or resigning themselves to occasional visits at considerable cost. When the unease that many parents feel about the institution and the unwelcoming tone reported by many parents when they do visit is added to this burden, it is not surprising that many families visit their son or daughter very infrequently. Within service structures people are frequently moved for administrative convenience and staff regularly move, get promoted, resign or at the very least, change shifts on a daily basis. This may lead to people having NO enduring relationships through their whole life. While people in South Africa could be moved at the whim of powerful people, the frequency of this dislocation probably did not match that in disability services.

In other areas of human relationships, parallels with apartheid are also apparent. Sexual segregation is common in institutional settings in a similar way to the single men's hostels under apartheid. However, people with a disability may be sterilised or injected with contraceptives without their consent, which seems to be more extreme policy than in South Africa. Under apartheid it was illegal to have sex between races. In a similar way, some aspects of criminal law still make it an offence for a non-disabled person to have sexual relations with a person with an intellectual disability. This is currently the case under Western Australian law.

Denial of Human Rights

One of the aspects of apartheid that most people found particularly repugnant was incarceration without charge. Black people could be arrested and spend months or years in jail without ever being brought to court. While some children were arrested in this way, the policy almost completely related to adults, and generally the term without trial was unlikely to go beyond two years. In striking comparison,

many people with an intellectual disability can be incarcerated from birth to death, also without trial or any due process. This occurs when a people are placed into an institution as children and live their whole lives there. In some institutions in America there was even a cemetery within the grounds.

When institutionalised the only appeal is to the Minister, in the same way as under apartheid, and they have effectively no chance of having anyone advocate to get them released. At least in South Africa, there was a chance that a prisoner might come to the attention of Amnesty or other activist groups.

When incarcerated, the systems of both apartheid and disability services further deny human rights. In South Africa many cases have been documented of abuse and torture whilst in custody - the most celebrated being perhaps Steve Biko. In institutions for people with a disability, similar abuse and maltreatment have been documented in report after report. It is very hard to brush aside these repeated examples as "isolated". In prison in South Africa, people were deprived of possessions. In disability services people are similarly stripped and deprived, whether by service charges that take the large majority of their pension, theft, lack of storage for possessions, or keeping money from them through public trusteeship.

While there are some reports of forced medical treatment for dissidents in South Africa, there is limited evidence for this. However, for people with a disability, involuntary medical treatment is a daily experience, primarily through drug therapy. There have even been quite well documented reports of people with a disability being used for medical experimentation, with the testing of radiation effects in the US being the most recently publicised example.

There are even parallels with apartheid in the killing of people. Many black South Africans were killed either through judicial means such as hanging, or "extra-judicial" means such as deaths in police custody or street killings carried out by members of the security forces. The people responsible for these killings were rarely brought to account. In the area of disability, services routinely offer genetic

testing and procedures such as amniocentesis and counsel parents on abortion of children with a disability. That is, they counsel parents to abort on the basis of disability, but would not condone abortion on the basis of, say, a child with the “wrong” gender. Similarly, a commonly shared experience of parents of people with a severe disability is the pressure to withhold treatment and even to withhold sustenance in hospitals. It is clear from the overt nature of these practices and the failure of those responsible to be brought to account that there is official sanctioning of the practices in a similar way to that which occurred under apartheid.

Underlying the denial of human rights in both apartheid and disability service is the treatment of people as less than fully human. Many of the above examples testify to this, as do examples of de-individualising such as treating black South Africans in stereotyped ways as “blacks” or Kaffirs”, and people with a disability being treated as “beds” or “the disabled”.

It might be seen that there is a major difference to apartheid in that people with a disability are entitled to the vote, whereas black people were denied this right in South Africa. However, in Australia with compulsory voting it would seem that failure to vote is effectively never followed up and there is little or no encouragement or training of people with a disability to take up their voting rights.

Exploitation

The exploitation of black people in South Africa was quite overt and little attempt was made to conceal this. Black people were seen as a source of cheap labour to carry out the needs of the South African economy and the white population. For people with a disability, there was some similar exploitation in the late nineteenth and early twentieth century, but with the decrease in employment in both the primary and secondary sectors of the economy this is less of an issue although it can be argued that it still does occur. However, there is often pressure from trade unions and business if sheltered workshops ‘undercut the market’.

In contrast, people with a disability are now critical to the society as a source of employment for valued people. Huge numbers of people are employed in this sector and they all earn at least a reasonable income. Certainly they enjoy a much better lifestyle than the people they serve. All of these people have very strong vested interests in maintaining the current system of services, and to look for new clients if their funding is jeopardised through lack of clients. Indeed it has been pointed out that our society is highly dependent on human services to survive in its current form (McKnight, 1977; McKnight, 1986) .

When we look at the individuals and groups who have a vested interest in services for people with a disability we could mention society, government, service agencies, service workers, professional groups, parents, commercial and public relation interests, and consumers of the people's produce. A very similar list can be drawn up for the beneficiaries of the apartheid regime. In looking at this list it does not take a great deal of insight to understand that with so many very powerful vested interests in services, it would be indeed surprising if the needs of the least powerful were met as a matter of course.

Lives controlled

A common characteristic of black people under apartheid and people with a disability is that their lives are almost totally controlled by others with more power. Federal, state and local governments can dramatically affect their lives through changes in laws, budgets, policy, residential zoning and such like. Agencies commonly refer to "our people" which in many cases is a very true statement - the people *are* "owned" by the agency. Parents may have a life-long control over people's lives, sometimes with statutory backing. People may be moved at the whim of the powerful, just as people in South African townships were moved to homelands with a change in policy. In South Africa people's lives were ruled by an ideology - apartheid. For people with a disability their lives are commonly ruled by ideologies such as institutionalisation, de-institutionalisation, economic rationalism, integration, normalisation and many others.

When we look at the lives of people with a disability, we often see that they have little or no control over where they live, who they live with, where (indeed if) they work, how much they are paid, how their money is used - even what they wear. In some cases they may have effectively no autonomy at all. In comparison with the apartheid system, it would appear that the control of their lives is in fact more extreme.

For both apartheid and disability services, there is a common issue in control. In both cases the people have effectively no involvement in real power.

There is also one other critical issue in terms of the control over people's lives. For apartheid, many in the west argued that sanctions were harming the black people and should not be used, but this was not supported by the anti-apartheid movement in South Africa as they knew that the stronger the economy, **the stronger the apartheid regime became**. Similarly, there seems to be a belief that as our economy improves, so will the lot of people with a disability. However, more money for services has meant greater control of the lives of people with a disability in the past. Indeed, it could be argued that many of the more community based services appearing at the moment, which often decrease the control of services over people's lives, are a result of financial restrictions from the recession.

Employment

For people with a disability, employment commonly means limited low status jobs paid at a tiny fraction of that paid to members of the valued culture. Many of the jobs in sheltered workshops are "make-believe" with no contribution to the society. They are in fact more in the nature of "day activities". Other jobs commonly relate to dealing with the waste products of the valued society, most notably through recycling. Even jobs in open employment tend to fall into a pattern that has been unkindly described as "food, filth or flowers". That is, there are very close parallels with the apartheid system.

In a similar way to apartheid, there is very high unemployment for people with a disability, even when sheltered work is counted as a

job. They even have their own trade union, as do black workers in South Africa.

The exploitation of workers in South Africa is clear, but in disability services it is commonly much more subtle. One way that exploitation occurs is through the “best” workers in a sheltered workshop not being trained for open employment as they are needed by the workshop to fulfil production commitments.

Education

The apartheid regime consciously used the education system to prepare black people for life as one of the underclass. It is hard to explain the segregated education system for people with a disability in any other way. The massive body of research clearly shows that people with a disability are advantaged socially and educationally if they attend regular education and **significantly disadvantaged** in segregated education (Calberg & Kavale, 1980; Dreimanis, Sobsey, Gray, Harnaha, Uditsky, & Wells, 1990) . Indeed, I do not know of one empirical comparison of segregated and integrated education that favoured segregation. Even if one has not read the research, the logic of segregating people with a disability, surrounding them with models who also do not have the appropriate skills and behaviours, giving them a low powered curriculum and poor expectations -- in order to teach them how to be integrated into society -- has a few problems with common sense. It is hardly surprising that research comes to the same conclusion.

Overall in education there are low participation rates for people with disabilities in regular schools, particularly in upper school and the education in segregated schools is generally of a poorer quality. This is very similar to the situation under apartheid.

For the education of the valued people, under both apartheid and our society the education of valued children emphasises difference and superiority to the devalued group.

Church Involvement

In South Africa, apartheid was supported by 3 Calvinist churches and in fact the “Broederbond” was established by a minister of one of these churches. All other Christian churches in South Africa opposed apartheid and this view was shared with churches in other countries. Black South Africans did attend segregated churches but had minimal involvement in integrated services due to legal restrictions. Over all, the main body of religious thinking was diametrically opposed to apartheid and saw it as immoral and unjust.

In comparison to this, disability services are supported by all churches and indeed they run many of the services. Despite many of the examples in this paper being drawn from such church-run services, there is almost no individual or group within organised religion taking a stand on these issues.

Underlying Assumptions

All human endeavour is based on underlying assumptions. They may be as basic as assuming we are going to be alive for the rest of the day, right through to deeply held beliefs about the nature of the world and our place in the grand scheme of things. We can often determine underlying assumptions by looking at the behaviour of organisations and societies over time. For example, if we look at Australian society over generations it is obvious the Aboriginal people are held in low regard by what has happened to them and is still happening to them. This is in spite of centuries of rhetoric that tells of care and concern for them.

If we look at the system of apartheid, it is clear that an important assumption is that colour of skin is a person’s most important single characteristic. The whole society was organised around this basic assumption. Similarly, for people with a disability, there is a fundamental assumption built into services that their most important characteristic is a genetic difference. If this is not the case, why would the society spend millions of dollars and employ legions of staff to serve people based on this characteristic? It is clear that the disability is more important than common humanity, shared skills and other characteristics that they might have in common with other

people, or special assets that they might have (Wolfensberger, 1988) . Other assumptions shared with apartheid are that the particular group should be segregated, congregated and “live with their own kind”. However, while the view shared by most of the world was that the racial problems of South Africa would be best solved by the dismantling of apartheid, our answer to the “problem” of disability is more services.

IMPORTANT DIFFERENCES BETWEEN APARTHEID AND DISABILITY SERVICES

While it is argued that there are many striking parallels between apartheid and disability services, there are some important differences to be highlighted. In South Africa, the apartheid policy was overt, written down, widely publicised and publicly supported by valued people in that society. In comparison, the real outcomes of disability policy are mainly unknown and the processes that drive services are primarily unconscious. Service workers and administrators do not consciously go to work with the intention to damage people with a disability. It is of course a common reaction to an analysis such as this paper for people to be shocked and upset - even hostile to the ideas and the person expressing them. The public persona of services puts forward a view of disability based on compassion, equity, fairness and other similar noble values and this image is accepted by most in society.

A second difference to apartheid is that while apartheid is based on a rationale of racial superiority, disability services are more likely to be built around a rationale of incompetence of the people and charitable work to compensate. While this may be a more noble rationale than for apartheid, the outcome does not seem to be too different.

A third major difference is that while the major benefits to white people under apartheid came from the cheap labour of black people, for our society the major benefits from people with a disability flow from employment, power, prestige and careers for non-disabled people.

One final and very disturbing difference between the two systems is that while apartheid was abhorred internationally and has finally been officially dismantled, services to people with a disability are acclaimed internationally -- and are growing apace.

IMPLICATIONS OF THE ANALYSIS

If this analysis is accurate, or even partly accurate, then it is clear that the lives of people with a disability are not going to be markedly improved by the provision of more or better services. Centuries of history show that we continue to treat people with a disability badly - but with the best of intentions. Clearly much of what we do in services is unconscious, and for this fact alone it is going to be extremely difficult to bring in fundamental change. The way that we treat people with a disability seems to be buried deep within our collective psyche. As such we are all participants in the system, whether as parliamentarians, managers, workers, parents or citizens.

Implicit in this analysis is the conclusion that the real function of human services is to meet societal needs, often at the expense of the recipients of the services. This is not to say that services cannot improve as there are many positive examples to be seen. However it seems that while some things change, others stay the same - the segregation, congregation, negative imagery and control of people's lives.

It seems that we are driven to carry out policies that harm people. A noble value of de-institutionalisation is perverted into dumping people on the street or other institutions such as gaols. 'Autonomy and rights' is perverted into denying vulnerability and responsibility for the welfare of others, often with tragic results. It is a sobering consideration that people with a disability often live out our grand schemes for the rest of their lives while we move on to other interests.

In conclusion, our current mantras of 'more staff', 'more money', 'more therapists...' clearly have to change.

Might I suggest 'Liberté, Fraternité, Egalité'. Particularly "Fraternité".

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