

WHAT IS IT ABOUT YOU THAT FRIGHTENS US?

A major group of Unpeople in New Zealand today are the intellectually disabled whose rights have been removed through legislation and whose lives are used up in the creation of work for people who otherwise might never get a job. These are the Unpeople that Justice Action Group frequently works to support. Their lives are a tragedy inflicted upon them from outside. But because they are Unpeople their tragedy is unremarkable, not newsworthy.¹



WHAT IS IT ABOUT YOU THAT FRIGHTENS US? WHAT IS IT ABOUT
YOU THAT FRIGHTENS SOME OF US SO MUCH SO THAT ALL WE
WANT TO DO IS HIDE YOU AWAY, LOCK YOU UP AND LOSE THE
KEY?

¹ The Unpeople of New Zealand. <http://www.justiceactiongroup.org/>

What is it about intellectually disabled people that make some of us, in this fair New Zealand, want to treat them like ogres and monsters? Thinking realistically it should be the intellectually disabled who are frightened of us, because some of us, particularly those with a lot of State power, act irrationally and often brutally towards them. The intellectually disabled should be frightened of us because of what we have previously done to them and what we still actively do.

Over the last century they have been subjected to experimentation, fed radio-active cereal, deliberately infected with hepatitis and given fluoridated water to drink before it was legal to do so. These experiments were carried out in the USA between the 1940's and the 1970's. During the Second World War many thousands were put to death in Germany just because they were mentally retarded. All were carried out by state agencies.

All around the western world they have been locked away in large institutions, forcibly removed from family and community, sterilised and abused for no other reason than their disability. And in New Zealand many unconscionable acts were done to them and are still being done to them. At present there are class actions against the State for what was done to them.



Over the last hundred years they have been viewed by us as criminal, promiscuous perversions of humanity or seen as not human at all. We began locking them up in large institutions before the turn of the twentieth century. We only closed the last large institution about a year ago (2007). And before the last one was closed we had started opening new smaller institutions.

We have segregated the intellectually disabled for as long as we have locked them away: away from their families, and away from the opposite sex, solely based upon a mixed-up evolutionary fear, that if they bred we would become a nation of morons.

Through our irrational fears that New Zealand might degrade into a land fit only for imbeciles we sterilised many thousands of them even while they were detained and segregated. We are still doing this, but now it's in their "best" interests not ours. We continue doing what we have previously done to them, but without the honesty that accompanied that era of eugenics. Now we hide what we do by calling it "rehabilitation" or some such. And we are still frightened of them!

Some people in this land have progressed a long way since those early days -but not all. Those that hold the power over the lives of the intellectually disabled - and in many cases their families - appear not to have moved at all. These are the dangerous people.

Counting up to twenty

There's a song by the same title. It tells us about people who can't count to twenty, not through impairment or age but because they cannot see the road ahead; cannot make the leap from old prejudices to newer more humane paradigms. They are destined to live in the past. But even if the rest of us are unable to help them see, we don't have to stay there with them.

There is however a problem. Many of these people that are holding fast to obsolete and prejudiced paraigms, hold positions of power within the State bureaucracies; and some perhaps, are even in Government; though it is the State bureaucrats that are the main worry for us. This is the way it has been for over a hundred years. Because they can't see the road ahead, they don't think there is a road and telling them that there is doesn't help because they can't see that road; not now, not ever.

There are those who become involved in what is colloquially called 'the Disability Sector'. Major groups include:

- those with a disability;
- the families of those with a disability;
- professional people and clinicians;
- management and staff who become involved with the service provider industry;
- State agencies personnel and Government.

The first two groups are most often involved involuntarily or at least initially so. They arrive by virtue of someone's disability. These two groups have the least power or influence in the Disability Sector, certainly in New Zealand. This is the way it has always been here.

The most power lies with State agencies, followed by a mixture of management and clinicians and professionals - followed up by Government. Running second to last are those who do the work at grass roots level.

However in terms of making positive change, there are only two groups who can and do make change: people with disabilities and their real allies (usually family and a few others who get involved for their own reasons).

Governments, who some believe are able to make change unilaterally, can only make positive or innovative change in response to incredible pressure by those two groups. They will not make change voluntarily, because they cannot. They have neither the expertise nor the political will. The expertise rests most powerfully with State agencies. In New Zealand that so-called expertise lies with the Disability Services Directorate (DSD) of the Ministry of Health and to a much lesser extent with professionals and clinicians, though psychiatrists as a clinical group do hold a lot of power on the basis of their pretended knowledge.

Social progress is never determined in committee, Government or Ministry. It comes from individuals sometimes banding together to achieve a particular social goal.

History revisited

About a hundred and twenty years ago large numbers of people with disabilities were sent to institutions. At the turn of the twentieth century the driving force for locking away all manner of people with disabilities came not from the general populace but from the nation's leaders: From ministers of the Crown, high academics, and noted medical people the call was to stamp out the perceived deteriorating quality of New Zealanders. It took more than thirty years just to stop the worst features of that bizarre and distorted paradigm. But what was being done to disabled people didn't stop and it didn't stop because they were perceived as less than or different to human beings. They were still locked away, segregated from the wider community and their family; and in some cases, sterilised - just in case. That situation, with some minor changes, e.g. moves to community living for the easy to look after, continued until the late 1970's in New Zealand.

With powerful pushes towards de-institutionalisation and community living overseas in more advanced societies the pace for community integration picked up here, though it never got out first gear until State bureaucracies believed there was a good reason to make the change. The “good reason” was saving money. However the problem that arose, even when the incentive of saving money drove them to dumping people into community based services, was that the skill resources were never at a level to provide the kind of care that some people needed.

With the passing of mental health legislation in 1992 the stage was set to reintroduce the intellectually disabled back to their institutions. Whether by gross stupidity or design, people with an intellectual disability which had previously been incorporated into the act were now left out. The necessary supports to pick up the people who were incarcerated at the time, had not been provided for, and they were dumped out of the mental health system with little or no supports. That set the scene for introduction of the Intellectual Disability (Compulsory Care & Rehabilitation Act) in 2003 (I D (CC&R) Act 2003).

Though the (ID (CC&R) Act (2003) was ostensibly drafted to rehabilitate criminal offenders and support people with very high and complex needs, the services provided to accomplish this task were wholly inadequate. The result was predictable. Good practice in this particular sphere, known long before the drafting and passing of the legislation, formed no part of the service provided. What was provided for was detention, and segregation.

The frightened people have always been in charge. Many of them are those people who fill out the ranks of the DSD, which they identify as meaning Disability Services Directorate; but we know it really stands for:

DENYING SOME DIGNITY

It leads us to question:

Who are these people? And who do they think they are?

What real authority do they have to act in contravention of the spirit of international treaties on the rights of disabled people?

What real authority do they have to ensure the continuation of service practices that falls far behind what is internationally considered and proven to be best practice?

What drives them to want to re-inter the living bodies of disabled people into whole-of-life graveyards?

Do they know what they are doing and if they do how can they in good conscience justify their actions?

That they continue along their aberrant path leaves us only the option of seeking their removal. We, as a civilised society cannot continue along the road to progress with a log across our path. It must be shifted.



What have they done now?

Below is a précis of the NEXT STEP. Taken from their SERVICE SPECIFICATION FOR A NATIONAL DISABILITY SECURE SERVICE, it describes the direction they are continuing to take. On the basis of this service specification we do not believe for one second that they believe in their philosophy statement but, if they do, then there are some very disturbed minds at work in that place.

They present their specification in terms of working within a framework of the New Zealand disability Strategy, identifying that:

The aim of Disability Services Directorate (DSD) is to build on the vision contained in the New Zealand Disability Strategy (NZDS) of a fully inclusive society. New Zealand will be inclusive when people with impairments can say they live in: 'A society that highly values our lives and continually enhances our full participation.'

They identify that:

With this vision in mind, disability support services aim to promote a person's quality of life and enable community participation and maximum independence.

- Services should create linkages that allow a person's needs to be addressed holistically
- In an environment most appropriate to the person with a disability
- Disability support services should ensure that people with impairments have control over their own lives
- Support options must be flexible, responsive and needs based
- They must focus on the person and where relevant, their family and whanau, and,
- Enable people to make real decisions about their own lives

IN A LONG TERM DETENTION CENTRE?

With this fixed firmly in their collective mind DSD are going to buy additional services to add to the ones they already have.

The Ministry is developing a framework of specialised services for people with an intellectual disability whose levels of need for behavioural support are so complex as to require specialist clinical support and intensive levels of co-ordination and agency interface. The definition of eligible service users includes those covered by the provisions of the ID(CC&R) Act and the RIDCA eligible civil population who are not subject to Court order.

What will be added to the present service options is:

National Intellectual Disability Secure Services, (NIDSS) based in Wellington and Auckland (Hospital level high forensic assessment and medium /long term placement)

Medium to long term placement for service users requiring secure hospital services (forensic high/medium dependency).

The people who will enter these services are:

- Whose behaviour has resulted in a breach of law, requiring involvement of criminal justice personnel (including Police, Correction or the Courts) or
- Who are being transferred under appropriate sections of the Mental Health Act 1992 and who show behaviour that poses a serious risk of physical harm to themselves or others or
- Who appear to manifest a psychiatric disorder, requiring mental health professional assistance for assessment, treatment or management (**also read Autism**).

A comprehensive range of hospital based treatment and rehabilitation options will be available to all service users, including but not limited to:

- Occupational therapy
- Social skills training
- Individual counselling and training
- Budgeting
- Domestic Skills
- Assertiveness and self esteem training
- Cultural assessment and development of appropriate cultural links
- Coordination of services
- Nursing, psychology and medical specialists (e.g. psychiatrists, neurologists etc).

Treatment strategies may include:

- Pharmacotherapy
- Psychological therapy
- Social treatments
- Education about illness, symptoms and the management of symptoms.

Natural Supports include:

Friends, both outside and in the service setting
Immediate and extended whanau members including hapu and iwi
Community activities/groups
Community education/courses
Neighbours and, Workplaces

Justice Action Group Work

Justice Action Group Inc. supports a number of people who are already incarcerated either for behaviour described as criminal or because they have high and complex needs, what they refer to as the 'civil population'. That means those people who have an intellectual disability and who cannot be supported within a community setting are to be locked away.

That might be seen as reasonable but only if the secure and community services were at the same standards as in some more progressive societies for people who fit into this particular group. In many cases they are not. For at least two reasons the quality of care in the community and in the secure units, of which two already exist, is substandard. New Zealand has neither the qualified personnel to do the work nor adheres to what can be described as best practice.

The secure units already in existence are the same as the proposed new ones. They offer the medical model of care. That is people with disabilities are treated as if they are sick, most of whom are not.

In more advanced countries the medical model of care has been discredited for well over twenty years. It has been discredited because it doesn't take into account the human dignity of people who do not need medical help but assistance to grow into a full citizenship role. The medical has been discredited here but not by the Ministry of Health and particularly by the DSD. If we take a close look at what is offered in their proposal it is obvious just how medicalised it is.

Treatment strategies may include:

- *Pharmacotherapy*
- *Psychological therapy*
- *Social treatments*
- *Education about illness, symptoms and the management of symptoms.*

These are the treatments of choice now in the secure units. What is described above means that people will be drugged into compliance since they are not sick (pharmacotherapy), and they will have psychiatrists and psychologists trying to 'fix' them (psychological therapy). Of the people we know in the detention units most are drugged into a level of compliance, not because that is the only available option. However in a closed environment many of the progressive options of rehabilitation are not able to be used. Also drugs are cheaper than employing a large number of qualified helpers. Many of those incarcerated do not have the intellectual capacity to take a meaningful part in counselling. They have intellectual disability and some also have severe autism spectrum disorders.

The rehabilitation options listed above will not see them released from detention. Budgeting, domestic skills, cultural assessment, occupational therapy, social skills training, individual counselling and assertiveness training is primarily window dressing for doing nothing.

In our capacity as advocates we meet, visit with and advocate for people described above, often over long periods of time. We often work with their family members who also are also advocating or who want help in improving the life conditions of their disabled family members who are in service care.

Prior to the passing of the Intellectual Disability (Compulsory Care & Rehabilitation) Act in 2003 we advocated for people held in institutional situations. We continue to do this for people with disabilities who are held in secure units. What we have found is:

The majority of people held there, stay in secure units for years with no noticeable improvements but often with increasing deterioration.

The medical interventions are based on drugging which is not a useful long-term solution and may well contravene international agreements on what a government can do to its citizens. Rehabilitation activities are often non-existent due to funding insufficiency and staffing difficulties, i.e. few highly trained and experienced staff to do the work.

Those detained often spend inordinate amounts of time being bored, spending time in their beds during the day, or having to attend therapy sessions which are of little use to many of them since they simply don't understand the process and the purpose of the sessions.

Activities that we would normally associate with young men, who comprise the majority of those detained, either do not exist for them or are pursued in a way that makes them unappealing.

Without doubt those people DENYING SOME DIGNITY will disagree and tell everyone, including themselves, that they are doing a fine job. We call that 'denial', that is, they don't like to face what they are really doing.

Similarly those of us who have to deal with what the DSD is doing, the families, advocates and others who have a real interest in the fortunes or misfortunes of people with disabilities in detention centres have to face up to the fact that we also live in denial. That is, we tell ourselves: things can't get any worse; things will get better; the people doing this are doing it for the best of reasons; and so on. Below is an abbreviated list of ways to live in denial. They are taken from Stanley Cohen's 2006 book, "STATES OF DENIAL: knowing about atrocities and suffering"²

- Turning a blind eye
- Burying your head in the sand
- Seeing what we want to see
- Ignorance is bliss
- Living a lie
- Conspiracy of silence
- It's got nothing to do with me
- Don't make waves
- I don't want to know/hear/see any more
- Wearing blinkers

Summary

Since 1994 New Zealand has been heading back down the road to 1894. The obvious intention of the ID (CC&R) Act is to return anyone with an intellectual disability who is not able to be easily supported within a community setting back into long term incarceration. It is a move which, like a juggernaut, will generate it's own momentum and with time become extremely difficult to stop.

Long term incarceration provides the state with an opportunity to renege on any promises of rehabilitation since there is no point if the detained are staying in a detention centre perhaps for life.

This goes against all the international treaties on the way people with disabilities should be treated. Though DSD prefaces its paper with the statement that the direction they intend to take is consistent with the New Zealand Disability Strategy what they are saying is pure rubbish.

What DSD is doing is best described as a 'con job'. Through fancy language and stealth they intend to turn the clocks back and they are relying on us to deny that it is happening.

We must, if we are to stop this destruction of people's lives, see past our own denials and determine to do something about it before it is too late.

² See Bibliography for full details

What we need to do is:

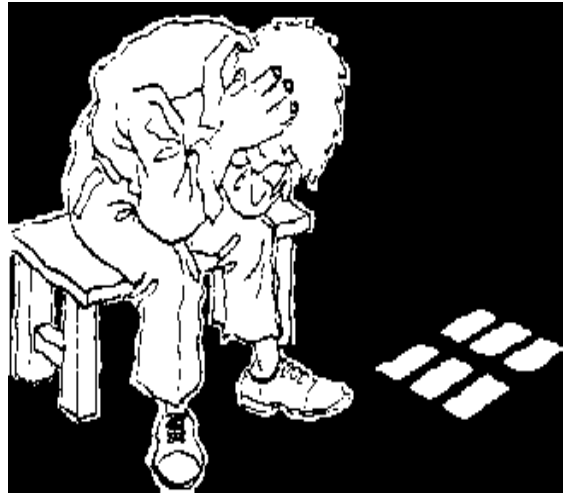
Talk about this problem

Get the word out

Get together

Get a plan

Do something



IF IT'S GOING TO BE, IT'LL HAVE TO BE ME

Bibliography

Cohen, Stanley. (2001) STATES OF DENIAL: knowing about atrocities and suffering. Polity Press: Cambridge