Autistic and Deprived of Liberty Under the Mental Health Act

Hilary Stace August 2016

A commentary on disability policy in New Zealand

Prepared for Ann Pettifor of Prime Economics and The Policy Observatory, Auckland University of Technology



About this report

This report is one in a series prepared for Ann Pettifor's visit to New Zealand in September 2016. The reports provide background information on challenges facing the New Zealand economy and society, and are available on The Policy Observatory website.

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Autistic and Deprived of Liberty Under the Mental Health Act

By Hilary Stace

How the powerless are faring is a good indication of the state of the country. In this paper I look at the case of an autistic 38 year old man who is incarcerated in a secure unit near Wellington under our Mental Health (Compulsory Assessment and Treatment) Act, against the wishes of his parents, his best interests and international human rights conventions. I suggest his situation may be due to fear and ignorance of disability and disabled people by a stretched and risk averse bureaucracy, rather than mental illness. It is likely we also have a wicked policy problem for which collective activism is the only remedial response.

There is a well-known saying that a society can be judged by how it looks after its most vulnerable citizens. People with impairments are not inherently vulnerable but are at particular risk of negative interactions with the state for a range of reasons such as a lack of a strong advocacy voice. People may have impairments but it is society which disables people. Hence the 'social model of disability' whereby disability is both personal and political.

Disabled and Locked up

Recent media publicity has revealed that one of our most vulnerable citizens has been seriously disabled by society in that he has been denied human rights, liberty and citizenship for many years. Why?

Ashley Peacock is a 38 year old man with autism who has been locked up under section 30 of the 1992 Mental Health Act in one of our mental health units. Despite numerous reports from authorities such as the Ombudsman, the Human Rights Commission, media, and even a warning under the Convention Against Torture, he remains there. He is restricted in the areas he can access and on numerous occasions he is locked in seclusion. He can only go outside when a member of staff takes him. But he has never committed any crime. His elderly parents want him in a community residential placement in a quiet rural environment where they can visit him and with support take him fishing and for the bush walks he enjoys. A provider has offered to train and provide carers 24/7 if a suitable house can be found. The District Health Board which in charge of his situation, insists (very unusually) that money is not the problem. So what is?

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New Zealand has often been prominent in the international human rights stage. Prime Minister Peter Fraser was one of the founders of the modern United Nations. In the publicity around later Prime Minister Helen Clark's bid to become the UN Secretary General, it was revealed that Peter Fraser was once approached to take on that role. More recently, New Zealanders took a leadership role in the development of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) which we ratified in 2008.

Robert Martin, who had a tough life growing up in institutions, spoke during the development of the CRPD in his leadership role with Inclusion International. This year he was elected to the committee which monitors the Convention. In 2007 New Zealand was awarded the prestigious Franklin Delano Roosevelt International Disability Award for contribution to disability rights. We have stalled in not signing the Optional Protocol to the CRPD which would allow individuals to take complaints to the UN, but that decision is currently before a select committee. We now also have a dedicated Disability Rights Commissioner in the Human Rights Commission.

During the development of the CRPD the New Zealand Mental Health Commissioner, herself a former psychiatric patient, championed Article 14 which includes the clause 'the existence of a disability shall in no case justify the deprivation of liberty' and guarantees 'reasonable accommodation' if disabled people are deprived of their liberty through any process.

But during these years of disability rights progress Ashley remained locked up in the mental health system. His parents sought help from numerous government agencies and non-government agencies without success.

But Ashley is not the only one. A recent case in the Wellington High Court was taken on behalf of three other adult men with intellectual disability/autism and assorted other health conditions who were held in secure units and (allegedly) forcibly medicated, secluded, denied facilities or possessions and harmed in various ways over several years. Their case came to court after several years of lobbying and advocacy by an Auckland-based organisation, Justice Action, which persuaded a prominent human rights lawyer to take their case on legal aid. Each man is claiming \$100,000 and \$25,000 for each year incarcerated.

Additionally, numerous cases of historic abuse claimed by those in state care, who were often merely children at the time, await resolution. They happened in the institutions of the state which included psychiatric and psychopaedic hospitals, residential schools, juvenile 'correctional' facilities, prisons and foster homes. The 1992 Mental Health Act was intended to signal a new consumer/client centred era with robust complaints pathways so such cases need never happen again. After a long process of deinstitutionalisation the last of the big institutions finally closed in 2006 and the remaining residents transitioned into supported accommodation in ordinary houses in the community.

A wicked policy problem?

Yet cases of disability abuse continue to appear in the media, often investigated by award-winning journalist, Kirsty Johnston. Why has it come to this despite our proud human rights record, how can we understand it in a policy sense, and what can we do? When an autistic adult is locked up under an inappropriate law without any obvious exit strategy I suggest we have an example of a wicked policy problem. I am not a medical professional, health provider or lawyer. My expertise is in autism and my PhD research was in autism as a 'wicked' policy problem. Wicked problems according to the Australian Public Service Commission are:

- Difficult to clearly define
- Have many interdependencies and are often multi-causal
- When tackled can lead to unforeseen consequences
- Are often not stable
- Have no clear solution
- Are socially complex
- Rarely fit conveniently within the responsibility of any one organisation
- Involve changing behaviours
- Some wicked problems are characterised by chronic policy failure (Australian Public Service Commission, 2007)

Autism is not mental illness

An indication of a wicked problem is a lack of a clear definition of the problem. Even the diagnostic labels which get people into the system are contested. The 1992 Mental Health Act created a label called 'Mental Disorder' that had a particular legal and clinical meaning. It did not take into account how those with autism might present, such as when under sensory overload.

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In 1992 autism was seen as a rare condition affecting perhaps 1 or 2 children in 10,000. They were nonverbal, seemingly quite impaired and often institutionalised. The condition was known as infantile autism, childhood schizophrenia, or mental retardation.

However, in 1994 the 4th edition of the American Psychiatric Association's Diagnostic and Statistical Manual included a new condition called Asperger Disorder in which people with autism could also be articulate and able and so brought many more children and adults under the condition. There were many families who now had a name for this puzzling condition and soon prevalence of autism was estimated at 1:100, a spectrum of conditions across the life span. Latest data from the <u>United States</u> has a 1 in 68 prevalence rate with 4 times as many males as females affected.

Clinicians looked at autism and saw deficits in communication, behaviour and obsessive interests. However, soon people with autism such as Temple Grandin were telling us what it was really like. She and others described an intensity of the senses in sight, touch, taste, smell and sound. She found other humans unpredictable and puzzling, which caused her much anxiety. Stress led to meltdowns which others saw as psychotic behaviour. She also described how medications often worked differently on people with autism.

There is the saying that if you've met one person with autism you have met one person with autism. But there are some things in common, such as a desire for order and predictability, fear of change, being literal, and anxiety often caused by other people. Clear written rules for everyone to follow helps. Many autistic people deal with the sensory overload or stress through physical activity. People often verbalise their thoughts or recite favourite passages of movies or TV programmes. Parents of people with autism use strategies such as social stories to warn when change will happen or visual or verbal cues to encourage self-regulation when meltdown threatens.

So the idea of 'Mental Disorder' for people with autism under the Mental Health Act is outdated and unhelpful. The New Zealand Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 was developed for those committing offences for whom the court process was inappropriate because of their intellectual impairment. But Ashley and others who haven't committed any offence remain locked up. Seclusion only increases boredom and trauma. He now has some additional conditions requiring attention.

Ashley was born too early to be diagnosed with Asperger's. He didn't get any targeted funding at school for the condition, was not protected from the bullies that autistic children face or live in a community with any understanding of autism sensitivities or meltdowns. So he ended up under the Mental Health Act.

In an example of inappropriate treatment he was recently removed from his room while it was renovated. He probably thought he was transitioning out into the community. A few days later he was put back in his room which now had vividly patterned carpet. There was no warning, no social story about the process of change. Any parent of an autistic child could have told you a meltdown was inevitable. He also had considerable unaddressed dental pain for years which likely exacerbated his behaviour and affected his drug regime. He's a lot more 'able' than many other people with autism who live safely and happily in the community - he is articulate and can make intricate fishing flies. So why is he still there?

Most articles of the CRPD are relevant to those held under the Mental Health Act. The CRPD is based on important principles such as presuming competence, reasonable accommodation, supported decision making, citizenship.

Hope through Community Activism

Wicked problems require innovation to tackle them and to challenge false assumptions and barriers - to dive into the conflicts and sort them out. What is working, although slowly, is an <u>unofficial activist community</u> which has developed around Ashley's parents. It includes people with expertise on autism, behaviour issues, medication, law, media and disability support. As a result of careful strategizing there has been a series of high profile media articles by Kirsty Johnston who is expert at requesting and interpreting official information, links developed with politicians, an on line petition and a high profile television programme. There is now the possibility of a pro bono court case.

As disability activists, we want the CRPD to be implemented. We want reasonable accommodation, the presumption of competence, supported decision making, and a legal system that works for disabled people and families, not against them. So it is time to review that outdated Mental Health Act to align it with the Convention. Meanwhile Government is working on a revision of the 2001 NZ Disability Strategy, and an Action Plan. It is not yet clear whether it will be strong enough to fight for the Ashleys of the world. While there are disabled people locked up in New Zealand merely because of their disability it will not be considered a success.

For more information see 'A Life for Ashley' Facebook page.

About The Author

Dr. Hilary Stace is a Visiting Research Fellow with the Wellington Health Services Research Centre at Victoria University, Wellington. Her research interests include aspects of disability and her 2011 PhD was on autism policy. Hilary is a regular contributor to the <u>Access disability blog</u> on the Public Address blog site.

About The Policy Observatory

Based at Auckland University of Technology, The Policy Observatory is a lens on public policy in Aotearoa New Zealand. We both conduct and commission research on economic, social and environmental policy issues, with the intention of publishing results in a form that is accessible to the general public. We work in a collaborative, networked way with researchers across institutions and in the private sector. Ultimately, we are concerned with how policy advances the common good.