



MZURI
— TRAINING —



The Horrors of Traditional Disability Care

by **Julienne Verhagen**

Understanding the past helps comprehend the fight for a better future.

Most people have no idea the true history of disability care, and what they have had to endure. If you don't know the extent of what has happened, how can you understand where they are coming from? I will also balance this with what some amazing organisations are doing and the extraordinary achievements different people are accomplishing.

To realise the extent of the violation of rights that people all over the world have had to endure because of society's inability to appropriately assess, label, treat and care for them, we need to look at the reality for many people over time. So, red pill taken, it's time for a history lesson.

People with a difference have been treated poorly throughout history. Children and adults with any sort of disability were:

- Killed or abandoned in ancient Greece
- Kept as jesters for the nobility in Roman Empire
- Killed as infants during the Renaissance
- Drowned and then burned during the Spanish Inquisition
- Housed in the basements of prisons in America in the early 1600s.
- Dehumanised in orphanages and asylums across Europe in the 1800s.
- In Boston in 1848, the "Institution for Idiots" was founded.
- In the late 1800s people were found handcuffed to their beds in institutions in America due to a lack of staff to care for residents
- In 1907, involuntary sterilisation began on people with developmental disabilities, to prevent the passing on of "inferior traits"

From the early 1900s disability was viewed through an "incurable" lens, so children and adults, particularly those with any intellectual disability, were put away "out of sight and out of mind" in institutions (Llewellyn et al., 2016).

People were housed in ways irrespective of their needs. People with cerebral palsy were considered mentally retarded, when it's primarily a physical condition. Deaf and blind people were also put into institutions as "defectives".

In October of 1939, Adolf Hitler stated that it "was the best time for the elimination of the incurably ill" and authorised the beginning of the "euthanasia" program. The physically and intellectually disabled, and the mentally ill, did not measure up to the Nazi concept of a "master race". They were considered useless to society, and ultimately, "unworthy of life".

“My continuing passion is to part a curtain, that invisible veil of indifference that falls between us and that blinds us to each other’s presence, each other’s wonder, each other’s human plight!”

Eudora Welty
(Pulitzer prize winning American novelist)

Doctors and nurses in hospitals were told to neglect patients, until they died of starvation or disease. Doctors eventually supervised the killings – sending patients to one of six different facilities where they were given lethal injections or gassed. Despite public protests in 1941, there is ample evidence that the Nazi leadership continued this program in secret throughout the war. About 200,000 handicapped people were murdered between 1940 and 1945.

Over the past 50 years (my lifetime) we’ve seen the following inflicted upon people with different forms of disability:

- Only allowed to attend “special” schools
- Inhumane treatments forced upon them
- Restraints applied – both physical and chemical
- Abuse prevalent (physical, mental, sexual, financial)
- Denied the right to work, vote or marry
- Often stigmatised in the media as sexually deviant, dangerous or criminals
- Being portrayed as “sickly” and needing our pity and donations, so that charities could thrive
- Victim of Inaccurate testing and diagnoses by uninformed practitioners – leading to inappropriate treatments, medications and unnecessary restrictions on livelihoods.

Residential care for people was similar in the Western World, where those with a significant issue, particularly an intellectual incapacity, was seen through a medical lens. They were considered “patients” and were “put away” in government and private institutions. These were usually large-scale establishments with nurses and hospital beds.

Let’s consider the basics here. It is well documented that all children need smiles, eye contact, talking and gentle touch, as well as basic food and water, in order to thrive. In addition to the stark hospital-like environment, many children growing up in these institutions were rarely held or kissed or spoken to, and there was little time for nurses to spend one-to-one time with any of them. Most missed out on these vital nurturing experiences. The food was basic, the medication rudimentary, and the effects from this lack of personalised contact would have been devastating – physically, mentally and developmentally.

Accounts of every form of degradation have been published. Inhumane punishments for certain behaviours, cruel therapies, rape, torture and extreme neglect. The emotional damage was no doubt beyond any of our comprehension.

In 1994 Murray Wass, a Washington-based investigative reporter published a story entitled “Bleak House”. At least 10 residents died within two years, in a Washington D.C. home for the mentally retarded. They died from an infection caused by entry of food into the lungs when patients are fed while they are lying down.¹ The staff hadn’t bothered to sit the people in their care up in their beds, not even to eat! Force feeding them caused aspiration pneumonia, which was left untreated and proved fatal.

Here in Australia we would like to think that we are more civilised than this. But in the mid 1970s a young woman, started to work at St Nicholas Hospital in Melbourne, when she met a young girl with cerebral palsy, who she began to work with.

“When I first met Anne, she was 12 years old, the height of a 4-year-old but skeletally thin, writhing on the floor at St. Nicholas Hospital, a state institution for children believed to be profoundly mentally retarded. “Who’s that?” “That’s McDonald. She’ll be dead in 6 months. We can’t feed her”.

No therapy, no education, no wheelchair, no toys, no clothes of your own and not enough to eat or drink – just the floor and a cot. It wasn't much of a life, but Anne enjoyed whatever there was to enjoy. She still had her trademark grin and wicked sense of humour. This probably saved her life, because it led me to choose her for a communication project when she was 16 and weighed under 13 kilos."

Rosemary taught Anne how to spell and communicate and Anne asked to leave the institution. Court cases, media reports and general condemnation from the establishment followed, but Anne prevailed and won her case. She lived with Rosemary and her husband for the rest of her life, achieving a university degree (using many different communication assistants) and co-writing the book which eventually was made into the film *Annie's Coming Out*.

Rosemary Crossley continues to be a controversial figure today – because she teaches people communication methods which include the physical assistance of another person, if that's the only option available to them. She works tirelessly – without any government funding, and only asking for donations from her clients – to help anyone who wants her assistance. Her tenacity, creativity and life's work is internationally recognised – while still discredited by others – and I believe she will go down in history as one of the true heroes of our time.

No doubt we must protect people with disability from manipulation and misrepresentation and abuse of funds. My position is that we must judge every case on its merits, and in order to do this we have to acknowledge any technique that can be proven – by multiple people being able to get the same results – to work. Otherwise we could be using our own judgements to severely limit others.

Societal changes started to occur in Australia the late '60s early '70s, and the government responded with the Handicapped Child's Allowance in 1974. This big change supported parents and encourage them to care for their disabled children at home. Public awareness also increased with the International Year of Disabled Persons in 1981.

In 2010 the Commonwealth of Australia, released the National Disability Strategy 2010-2020. This has paved the way for other ground-breaking reforms, the signing of the United Nations Charter for People with Disabilities and the complete change in the funding process for people with disability with the new National Disability Insurance Scheme (NDIS).

This scheme, bought in by Julia Gillard's Labor Government, aims to provide individual funding to provide appropriate care and give genuine choice to all people with any form of disability. The intent is for everyone to have an inclusive, educational, individual and forward-looking life as possible. The reality has been met with some huge challenges to that ideal, but this is where we are at in terms of government and societal ideals.

In general, people with any major sort of physical, social or intellectual difference were treated under what we now call the Medical Model. People were labelled in terms of disease, abnormality and "personal tragedy", and if they couldn't adapt to fit the world they were shut away out of sight 'for their own good'.

"If you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid."

Albert Einstein



While I do still see evidence of this today, as a society we have definitely moved on from the Medical Model, into what's called the Social Model. The Social Model takes the blame off the person, looks at their condition rather than 'disease' and from the person with disability's point of view says: "Here we are. We are part of society, and the only real limitation we have is from you as a society not making things accessible to us."

The Social Model was developed by activists who started the "Independent Living Movement" who see the barriers created by society, such as negative attitudes and inaccessible buildings and transport, as the cause of disadvantage and exclusion, rather than the impairment itself.

Doctors are still here to help, but it's governments and schools and workplaces that must make the effort to be inclusive, and to provide access to services. The majority of people with disability don't need nurses, they are not sick. They need people to assist them do the everyday things that any person would need and want to do.

With this new movement came ramps at the front of buildings, wheelchair accessible platforms for trains, and schools were mandated to accept people with disability – with assistance – in regular classrooms. Workplaces now cannot discriminate against people with disability and when the right job match is found it's a fantastic benefit to all. Supermarkets are starting to host 'quiet hours' where people on the Autism spectrum (ASD) or with sensory issues can shop with dimmed lighting and loudspeaker announcements or music so prevalent the rest of the time. (If yours doesn't offer this, perhaps you could request it. That sort of thing gets them great local publicity, and will certainly help more people in the community.) Libraries and other public places are waking up to the effects of fluorescent lights on those with epilepsy and ADHD, and the Companion Card program, (where people who need to have another person with them to attend any event, movie, museum or theatre show are not forced to pay twice to gain entry) are all examples of the Social Model in action.

Yes, we've come a long way – in many ways.
Yet, for some people not a whole lot has really change very much.

A World Report on Disability was released in 2011. It clearly stated that being disabled led to a greater risk of being exposed to violence and a higher risk of premature death, but not because of their disability. The risk was from violence and poor-quality health care.

One statistic that jumped out at me was that, in "high income countries" 44.3% of males and 54.6% of females tried to access health care but were denied it.

Using 2012 Australian data, we know that Aboriginal and Torres Strait Islanders had higher rates of disability than non-Indigenous people across all age groups; and overall are 1.5 times more likely to be living with a profound/severe limitation.⁵

The Australian Bureau of Statistics (ABS) released summary findings that same year of A Survey of Disability, Ageing and Carers. It showed that violence against people with disability in institutional and residential settings is "Australia's hidden shame". The evidence of this national epidemic "is extensive and compelling, and this blight on our society and can no longer remain ignored and unaddressed"

"Action is the antidote to despair."

Joan Baez

“All we need to do is make sure we keep talking.”

Steven Hawking

In 2015 A Community Residential Unit (CRU) on the Mornington Peninsula in Victoria was found to have been a “house of horrors” for over 20 years. The report tells of multiple and systematic rapes, threats and physical assaults. Stomach-churning accounts surfaced of people whose attempts to raise the alarm were ignored. This group home provider not only did nothing to fix the situation, but victimised the whistle-blowers. The known rapist and violent monster - alone with these terrified people, night after night – resigned before he could be sacked, and no staff have ever been disciplined. The house is apparently now well run, but the accounts of what happened there were too disturbing to recount.

The number of people with disability that are being drugged as a way of managing behaviours of concern, are frightening. It’s a practise known as “chemical restraint”, and on the 18th May, 2017, the ABC (Australia) reported that 99% of people with an intellectual disability, and living in a group home, were on psychotropic drugs, but only 46% actually had a mental illness.⁸

The Australian Government produced a document titled: “Understanding safeguarding practices for children with disability when engaging with organisations“ in 2017. In it they state that “Children with disability have a nearly four times higher risk of experiencing violence than their non-disabled peers.”

So, what are the risk factors for this abuse? Why is it still occurring?

In 2011 the World Health Organisation (WHO) looked at eleven studies which met their criteria for inclusion in this meta-analysis: none were Australian.

The following risk factors included:

- segregated settings;
- children with disability being alone with an adult;
- closed and locked settings;
- organisational culture and attitudes such as those supporting a culture of closed communication; and
- poor leadership and organisational governance.

In August 2015, The Australian Cross Disability Alliance wrote a “Submission to the Senate Community Affairs References Committee Inquiry into Violence, Abuse and Neglect against People with Disability in Institutional and Residential Settings”. In it they wrote:

“It is almost impossible, in a written Submission, to do justice to the magnitude of the issue of violence against people with disability in institutional and residential settings in Australia.”
(23 Australian Cross Disability Alliance, Submission 147, p. 6.)

The Committee also stated:

“It has been a challenging task for this inquiry to adequately capture the scale of the epidemic of violence, abuse and neglect of people with disability and the toll this epidemic has had on individuals and their families....In the words of one witness to the inquiry: “We bear witness to the stories and Australia’s shame.” ”

(Ms Peta Green, Bolshy Divas, Committee Hansard, Perth, 10 April 2015, p. 11.)

On the 2nd February 2018, the office of the Disability Services Commissioner (DSC) stated that during the 2016-2017 financial year, 356 allegations of staff-to-client physical or sexual assault were reported to them.⁹

So serious abuse really is happening, right here, right now. We need immediate change. To finish off this hall of horrors, it is important to note that while all the various governments since the 1970s have been promising to close the big institutions down, currently six large institutions remain in Victoria and South Australia with more than 500 residents in them. I have no information on how well these institutions are run, and given the rate of abuse in smaller group homes I'm not sure that closing institutions, without a proper plan of reintegration into society, is the best answer.

I believe change will only come when the expectations, safe-guards and policies reflect 21st century standards, and providers start being more concerned about their clients than their reputations. But it is a fundamental right to at least be living within the community, as a human person.

A young man with cerebral palsy in a Melbourne was systematically being abused by a male nurse in January this year, 2018. After raising concerns, which were ignored, his family did something that is illegal in aged-care and group homes – they hid a camera in his room. What resulted was clear footage of the physically abusive behaviour by the male nurse. Not only did he momentarily strangle him and rough-handle him, but it seemed clear that this was a regular occurrence.

The footage was splashed all over the news, and received widespread condemnation. But what about all the times when concerned relatives have abided by the law and not put cameras into their family member's room? What about those people who have infrequent or no family visitors to raise questions?

Who is going to be brave enough to be the first service provider to have mandatory motion detector video cameras (CCTV) in every room – monitored on a regular basis - as a matter of course?

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Melbourne Office

Level 9, 440 Collins St,
Melbourne, Vic, 3000

Phone: (03) 8692 7237

Mobile: 0421354332

Email: julienne@mzuritraining.com.au

www.MzuriTraining.com.au

