



Unfettered Ability

OPINION | Cheryl McDonnell

Being the parent of a woman with severe disabilities involves challenging and changing learning curves. In 2010, I resumed the care and responsibility of my daughter who was then 22 years old. She had been the responsibility of another person for six years. While it had been difficult for me to step aside in 2004, it was necessary for my mental and physical health to do so and I was confident that the person taking over the care and responsibility of my daughter had sufficient love, skill, and nous to carry out the tasks and make the decisions necessary in my daughter's best interest.

Over the almost three decades of parenting a person with a severe disability I have had to learn new vocabularies - a medical vocabulary and a disability vocabulary. There are words and turns of phrase used in the medical and disability arenas of life that are not in commonplace language and are seldom understood by the general community. I needed to learn and understand these words to know how to best help my daughter.

While it is true that in some cases it is necessary to introduce new words and turns of phrase to name and describe medical and disability specific ideas, procedures, and understandings, in my experience it been used far more often in the disability arena to cover up or jargonise actions, procedures and ideas that would be thought of as wrong, abusive, and even torturous if they were applied in the general community. The implementation of 'restrictive practices' fits into the latter.

The idea that we as a society have a need to restrict, limit, change, and even, normalise behaviours, choices, control, words, and actions of people with disability has led us down a path of accepting abuse, so long as it is dressed up with an acceptable 'disability term' or jargon. When a person sits at the table in a restaurant and rocks persistently and calls out loudly there is a general desire among people surrounding them to hinder, restrict or control these behaviours. Yet, in

fact these behaviours, previously hidden from society by the institutionalisation and segregation of people with disability, are nobody's business but the person displaying them. To see such behaviours may make other diners feel uncomfortable, concerned, or may inspire other feelings in them, the behaviours themselves are not their business to comment on, or control, yet many in the community would comment on and even attempt to or actually control the behaviours for a range of reasons from attempting to assuage their own fears, to having deep concern for the person displaying the behaviours themselves.

This idea that there is a need to restrict anything that is different to societal norms results in the implementation of restrictive practices and the acceptance of these practices being in the best interest of the person subject to them and yet they are implemented to make society feel better about itself and are a rejection of the person displaying the behaviours as a valuable part of society as they present.

While some people may find some behaviours evident in the general community annoying, such as twiddling hair, pencil nibbling, or cracking knuckles, there are very few people that would act to prevent these behaviours in members of the community without

disability, and fewer still that would address the behaviour with a total stranger without disability. It is the presence or perception of disability that makes it somehow acceptable to intervene in behaviours that have, until recently remained mostly hidden from view by the policies that locked people with disability away from the community. It bears noting that just because you are not familiar with a behaviour, a lack of familiarity does not make the behaviour wrong. Many behaviours are neither right nor wrong and are simply an indication of the diversity of humanity.

In public places when my daughter and I are going about our own business and she displays a behaviour that might be perceived as new or different to other people's behaviours, I have been asked to limit, control, or change her behaviour and have been threatened with being reported to police, welfare or other authorities if I ignore the requests. I ignore all

requests to change her behaviours and all threats because my daughter has an equal right to be in any public place as anyone else. She also has the right to present herself in any way she chooses that is within the law of the land.

My daughter, and I by extension, have been subject to controls, restrictions, limitations

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based on our real or perceived disabilities and often these controls come in the form of policy changes or implementations to effectively limit my daughter's behaviours or my ability to advocate for her freedom to be who she is as she is without unfair or biased restrictions that restrain her behaviour and/or my words and actions that are advocacy for her freedom from restraint.

For the six years my daughter was not in my care she was subject to the use of a wheelchair as a restraint on her freedom of movement. While she had, had a hospital bed so that I could raise and lower it while she was too big to lift and had not yet learned to stand, her hospital bed had no rails, rather it was one that could be lowered very close to the floor that meant she could crawl in and out of bed as she chose throughout the night. This was replaced, in my absence, with a hospital bed with rails that in effect became her night time cage. She was not given any means to communicate, and she was not asked anything. She was treated with little more - and at times less - humanity, than a doll in a toy stroller. Her mind, body and spirit atrophied.

Belted into a wheelchair with the brakes

applied in a manner so she could not release them and she was subject to what amounts to kidnapping by staff at various institutions, (school, day programs, respite facilities) as she was wheeled from place to place without her consent and without her ever being asked if she wished to go anywhere. She was not given the option of spending time out of the wheelchair. She was not given choice over activities, or outings, and she was in fact restrained physically, mentally, and emotionally from being herself.

Staff from an agency that was paid to provide my daughter with support simply regularly kidnapped my daughter, took her to their place of residence, left her in the lounge room with other staff family members and then the staff member went about her own daily household chores ignoring my daughter and her need and right to have choice and control over her own life. She was given no agency in her life and no one offered her any means to communicate her wishes.

For six years my daughter was dressed in clothes not of her own choosing, but simply for the convenience of family and paid staff. The clothing added to the infantilising of my daughter, being mostly in shades of powder blue and baby pink tracksuits.

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Perfectly capable of sitting on a toilet or a simple kitchen chair since the age of six and capable of standing at a rail and holding on, capable of drinking from a cup and eating fingerfoods without assistance at age 16 she was restrained and restricted by practices and policies over the ensuing six years. At age 22 she presented with leg muscles so atrophied that they were not visible, standing physically hurt her, and she curled up at every opportunity and withdrew from all attempts to interact with her. My daughter showed no interest in holding her own cup and no interest in picking up food for herself. In six years she had gone from a vibrant young woman with a rich sense of humour, distinct likes and dislikes, occasional speech, strong in mind and body to an infantilised, even dehumanised, version of her former self.

Limitations included not permitting her to give herself food, as this sometimes made a rather inconvenient mess for staff to clean up. She was prevented from holding her own cup and drinking at her own pace as this too could end in an inconvenient mess.

It took months of untangling the trail of practices, policies and procedures that had so severely restrained and restricted my daughter to understand exactly what had caused her to regress. For many months more I worked slowly and surely to draw her back out into interacting with the world and regaining her

previous levels of independence.

Often people who have worked in the disability sector for a long time are the people who are so used to implementing restrictive practices that it has become an immediate answer to every problem, even when other solutions present themselves.

When my daughter required an operation on her eyes I was concerned that following the operation she may rub at, press or otherwise hurt her eyes. I decided to ask her case manager to request extra support worker hours in the first few days following the operation so that someone could be in my daughter's room ready to distract her hands away from her eyes. As my daughter has her own funding that would cover this extra support the cost was not a 'departmental' issue but we did require the case manager's approval to get the funds released from a trust fund.

The case manager's response was to insist that a pair of mitts fitted to my daughter's hands was sufficient to prevent damage to her eyes. I was not so sure. My daughter is blind. She uses her hands to 'see'. She also has neurological sensory processing disorder which means that many textures, sensations, and some textiles will irritate her and some cause a great deal of distress to her. I explained all of this to the case manager who in turn dug in her heels and insisted that

it would be the mitts or alternatively I could sit up all night and watch my daughter or I could ask the doctors at the hospital where the operation was to take place to prescribe sleeping tablets for my daughter.

I could not care for my household all day and spend all night watching my daughter, I have long ago conceded that I am indeed not superwoman and have no intention of trying to pretend otherwise. To use medication to make things more convenient for anyone is wrong and I would not ever agree to a chemical restraint for my daughter.

To buy time while I thought things through I agreed the mittens could be purchased with my daughter's money. On their arrival I visited the website of the manufacturer to find they were indeed listed as a restraint. I investigated the use of restraints and found that most organisations that might use a restraint on a person had policies to say that a person who is subject to a restraint must be in full sight of an active support worker. I thanked the manufacturer for this information and rang the case manager to tell her the restraints had arrived and that it is recommended that while the restraints are in use that my daughter would require constant supervision. The mitts still float around our house somewhere but they have never been on my daughter's hands.

Other than boredom busting behaviours like biting her own hands to the point that callouses formed during those six years and a rather painful adolescent stage of performing nipple cripples on anyone who stood too close which she learned was unacceptable and eventually stopped doing, my daughter had never caused harm to herself or others.

The *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* states:

People with disability who are supported by disability service providers and engage in challenging behaviours that are perceived to be harmful to themselves or others are at risk of being subjected to restrictive practices.¹

My daughter's experience tells me that this does not go far enough to state the situation of restrictive practices. She is not known to be harmful to herself or others and yet in 2010 her life was full of restrictive practices and restraints. I would say that it is more accurate to say that any person with a disability is at risk of being subjected to a restrictive practice. The Australian Law Reform Council states:

While restrictive practices may be used in some circumstances there are concerns that such practices can also be imposed as a means of coercion, discipline, convenience, or retaliation by

staff, family members or others providing support. Such practices may infringe a person's human rights. As a result, there are significant concerns about the use of restrictive practices in Australia.²

This is a more accurate account of what happens. The implementation of restraints and restrictive practices is not limited to those who harm themselves or others, rather, it is a tool that is all too often used to make providing support and care more convenient for the support worker or the service provider. Many practices that limit the freedom of people with disabilities are undertaken in preference to taking the time required to discover what practices would be required to support the person with disabilities to grow, develop, learn and have new experiences.

There are organisations working to resolve behaviours that might cause harm to self or others in ways that look at supporting the person rather than restricting the person. For example, the Australian Psychological Society (APS) advises their members:

Challenging behaviour is mediated by a combination of interpersonal, organisational, and environmental factors. Clinicians should assess the impact of environmental factors on the occurrence of challenging behaviours and modify the environment where possible to meet clients' needs and

sensory preferences.

[...] There are many ways to stop behaviours of concern and to do so with safety and dignity for clients. These methods should be used before restrictive interventions are considered. The use of physical restraint places both the person subject to the restrictive practice and those implementing the practice at serious risk of harm, trauma or, in worst case scenarios, death. However, there may be times when the use of restrictive practices becomes unavoidable. Moreover, these practices should be used only as a last resort. In such circumstances, it is important that respect for clients, and their dignity, remain paramount at all times.³

Restraints and restrictive practices are so commonplace in the disability sector that it becomes difficult to identify any difference between a restrictive practice and violence. Whereas violence against women with disabilities can include forms of abuse that all women can experience - including incest, beating, rape - violence against women with disability can also take the form of withholding medicine or support, forced sterilisation, removing a wheelchair, ramp or white cane.⁴

Is there a difference between removing a wheelchair from a wheelchair user and placing a person in a wheelchair with a

lapstrap belt and applying the brakes? Both have the same effect of limiting personal freedom and movement for the convenience of someone else. Likewise, with medication. What difference is there between withholding medication and thus increasing the debilitation of the person or increasing medication to increase the debilitation? What difference is there between removing a white cane and placing the hands of a blind person into mitts?

Article 14 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD)⁵ clearly discusses the right to liberty.

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:
 - b. Enjoy the right to liberty and security of person;
 - c. Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

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These days, my daughter stands at handrails holding herself up at the beach enjoying the ocean breezes. She has a means of communication and makes choices about her daily life and has a means of making decisions on issues that affect her. Wheelchairs are used for longer distances and she does not have to stay in her wheelchair if chooses to leave it. The wheelchair goes where she says it goes and the brakes are only used to stop her rolling down hills!

As the restraints gave way to freedom, my daughter took more interest in everything around her and she enjoys every aspect of her freedom.



About the Author

Cheryl McDonnell is a cross-sectional social justice activist and member of Women With Disabilities Australia (WWDA), People With Disabilities Australia (PWDA), and NSW Council of Social Services. She is a person with disabilities and the parent of people with disabilities. Cheryl enjoys gardening and the arts.

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Endnotes

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