

Labels do not just *describe*; they also *judge*.¹

Overview

Justice Action Group (JAG) is an independent advocacy organisation in New Zealand. JAG advocates for people with intellectual disability and other cognitive impairments. It does this through direct advocacy and by supporting others who are trying to do the same. This often means ‘family’ members. JAG also employs systemic advocacy to bring about organisational, political and societal change.

This presentation focuses upon the demonization of family members who advocate for their relative with a disability. Over the 14 years of its existence JAG has supported many family members in their advocacy. We have observed how human service organisations, government ministries, and other agencies have used the demonisation process, whether knowingly or not. The manner and purpose of the process and result is the reason for this paper.

This paper and the presentation are an exploration of the idea of “Demonisation”. Audience participation and input for this discussion is welcomed.

For many people with severe intellectual, cognitive or physical disabilities the only protections that they will have are those provided by people who care about them. These advocates may be family members, citizen advocates and other independent advocates, or direct care personnel who sometimes become advocates. In our experience other advocacy agencies in New Zealand, usually state funded, do not protect the people referred to above, but often have conflicting and other interests and agendas.

For independent advocates the personal cost can be high, particularly when the person being protected is very vulnerable. This paper is about that high cost. It is also about what needs to occur to create “Trusting Partnerships” between providers of services and families or other advocates. If we define partnership in the very positive sense of an alliance, collaboration and mutual cooperation, then, in our view, there is a very long way to go in New Zealand. We have a very long way to go before there is anything like equality of power within the service delivery system for people with disabilities.

There is no easy resolution since the protections that vulnerable people with disabilities need, will persist unless there is a sea change in human behaviour. Therefore people who work outside of the state system to better the lives of people with severe disabilities will, hopefully, persist. Since the power lies with the agencies that are entrusted with the care of people with disabilities they must recognise that with the power comes the responsibility to make the necessary accommodations, if anything like a trusting partnership is to be achieved. “Trusting Partnerships” may be occurring overseas but in New Zealand, in our view, it is a rare phenomenon.

In our experience, both the people with disabilities and their families are left a long way back in the “need to get along with and be accountable to” list. This we see

¹ See Bibliography Khaled Abou El Fadl

because service provider organisations have so many other conflicting interests and responsibilities to more powerful agencies, i.e. funding services and state agencies. Additionally it is those with disabilities and their families that tend to cause the most challenges for service provider agencies. In particular, family members have higher expectations from services relating to ‘family concepts’ rather than funding or political matters. They want a good life for the person they support and to achieve this they often have to resort to vigorous personal advocacy. That advocacy may come at a high cost ‘Demonisation’.

Investigating the idea of “demonisation” has also brought into the inquiry whether or not it is males or females or both, who are more susceptible to being demonised. We don’t know any males who we could say have been demonised. But then in our experience there are many more mothers than fathers of people with disabilities who advocate. This can be for various reasons – e.g. single parent responsibilities, mother, the main home helper/visitor. Also are women more prone to demonisation than men.

Women are more likely to be demonised when they act outside of the preconceptions that society holds of ‘motherhood’ (Naylor: 2001). The preconception includes the notion of ‘Coping’ which Naylor describes as a “compulsory element of the maternal role”. Therefore asking for assistance with her role, or failing in that societal preconception, brings them attention, “of the most damning type”. A question might be raised here about whether there is an issue of ‘caring and coping’ if the child is in ‘care’. Does that infer that the mother was somehow lacking?

Mothers are also likely to be demonised when they step outside the societally perceived role of ‘caring’. For example, if they are viewed as violent, when issues of mental disorder present, or when they become dependent, particularly if they are mothers on welfare. Marital and emotional state also plays a role.

So what do we mean by ‘demonisation’.

Some definitions of demonisation include: Making demon-like; a source or agent of evil, harm, distress, or ruin; to turn into or as if into a demon; to possess by, or as if by a demon; to represent as evil or diabolic.

It becomes obvious using the above definitions that demonisation will likely be used when no rational response is available to the questioning of a particular stance or decision made by state or service provider agencies. The questioning of decisions becomes a challenge to the current thinking or practice and as such may be viewed as disobedience. Advocates challenge in the courts². They challenge in the media³ and in other forums.

In our experience of parents challenging processes, decisions or policies made by service provider agencies, government ministries and other state funded or directed agencies, the first response is to ‘reason’ with parents. This we see as a euphemism for getting them to see it the ‘right’ or the ‘official’ way. If and when this does not occur and the challenge remains, ignoring the offending parents or placing barriers in

² NZ Herald , October 11, 2008. Catherine Masters

³ NZ Herald, June 21, 2008. Chris Barton

the way to hold up the process is a common ploy and has the desired effect of disheartening and 'wearing down' the challengers, and if that doesn't wear them out 'demonisation' may occur. However all three may well be occurring at the same time.

The challenges might aptly be described as 'disobedience', or the challenging of authority. Disobedience is the single most powerful creator of change. Oscar Wilde asserted that disobedience was man's original virtue and through disobedience that progress occurs. Henry David Thoreau identified disobedience as the true foundation of liberty and that the obedient are merely slaves, while George Bernard Shaw called disobedience, the rarest and most courageous of the virtues.

What occurs in the process?

"Of course demonisation is not new. The process of comparing individuals or groups to demons, or portraying and perceiving them as evil, wicked and inhuman has long been a feature of relations between and within groups." Damnation of entire groups requires the perpetuation of negative stereotypes, where the individual's identity is subsumed by that of the group. No diversity is admitted." Milojkovic, Svetlana. *The Media's Demons*:

Some descriptions relate demonization to historical stereotypes of a vicious nature, of evil but it can also be a subtle, subconscious, archetypal perception. William M. Arkin in a Washington Post article⁴ discusses how he became perceived by those who did not like his stance on the war in Iraq. He wrote, "I have become the enemy and have been demonized. In that process, I have ceased being a person, an individual, or a human being, all essential to justify the campaign to annihilate me."

Demonisation works! If it didn't we would do something else. And there is always a reason for demonising. A well known example is the "Tampa" incident involving a refugee ship off the Australian coast in 2001. The arrival of the ship coincided with the general election. It was a perfect opportunity for the incumbent prime minister who, polling had shown, was trailing the Labor opposition.

The arrival surfaced "ugly and vicious outpourings of hatred... in discussion of boatpeople/ illegal immigrants", and, "nascent racism, ancient fears of invasion by immigration" among Australians (Marr & Wilkinson: 2003). These feelings within the community became a political force that the prime minister was able to use to his advantage in the election. There were stories in the papers about mothers throwing their children over the side of the ship and of children's lips being sewn together. In this example the actions were public but the reasoning, the why, was covert. The prime minister was defending Australia publicly, but it was really about an election. The prime minister was re-elected.

Demonisation is a tool for silencing debate, used for character assassination, denigration, creating an enemy, and causing guilt by association (Desch: 2007). Labelling dissidents, 'complainers or troublesome', is a very effective way of silencing criticism.

A little while back in New Zealand nurses were talking about going on strike for better pay. Their opposition raised the spectre of death. People might die in hospitals

⁴ Demonization and Responsibility" 6 February 2007

if the nurses go on strike. Real nurses don't do that. Is this demonising? How much impact did that kind of media coverage have on forcing a deal?

Golubeva (2007) asserts that through the demonisation process adversaries are turned into enemies with whom no civilised debate is possible, and “justifies extreme measures, and sets up barriers to criticism so that opposition or questioning is itself a mark of guilt” (Barker; 2008).

The demonisation of Saddam Hussein by claiming that he had weapons of mass destruction (WMD) were a useful invention to provide an excuse to invade and to stifle the arguments against an invasion by claiming imminent danger. Later when it became clear that there were no WMD's it was too late. The invasion had occurred, Iraq was occupied. The actions were public, the reasoning covert. And even now, years later, WMD is a term that is widely understood by the public.

Demonisation for the purpose of this presentation is a covert thing. Unlike the examples above where we see it being done, think we know why, but usually don't, it is not always easy to find evidence that the demonisation has occurred in the area of disability. It might be termed a whispering campaign.

Sometimes it's just a feeling that someone has. Something that has been done to them. They might not even recognise it as demonisation. The person might feel powerless and say, “They never listen to me”, or, “I might as well not be there. I don't think they even see me”. Or it may result in a paralysis of action, “What good will it do?” Or it may be stronger than that. “If I do this then those people will attack me and if I do that the other people will attack me. I can't win.”

So there is always a purpose or many purposes behind the demonisation. Different people may become involved in demonising the person to bring about different outcomes.

Another example is in the area of family governed or based services for people with disabilities. Right now there is a court case going on about this. The Ministry of Health are involved and are against family members being paid to care for their relatives with a disability. One argument aired by the ministry in court is that family members should not be paid to care for their own children, as it contradicts part of a 'social contract' between the state and families. Another argument includes the likelihood of a flood of applications and the subsequent enormous cost to the government (Masters: 2008).

We know of a number of families who want this for their own sons or daughters. We know of one or two of them who believe they have been demonised, although they perhaps would not have used that language. We know that the demonisation process penetrates into many other areas outside that of disability.

The courts are one area where demonisation can be very effectively pursued since what is said is often legally suppressed, i.e. prevented from being made public knowledge. Courts may call upon specialists, clinicians and other reports not public and make decisions based upon those reports without anyone outside the court having access to that information. That information is not always accurate. It may be

purposely slanted. One of the main purposes of demonisation is to delegitimise and invalidate any views of that person, family or group being demonised. Suppression of information makes demonisation very much easier.

Perhaps one reason for the lack of discussion about 'Demonisation' is that other terms have commonly been used within the disability sector in terms of the attitudes prevalent within the sector and the wider community in relation people with disabilities. One such term is 'devaluation' (Wolfensberger: 1991). Wolfensberger explains that all of human perception is evaluative, that is, we judge everything either consciously or unconsciously. When we judge humans negatively we tend to devalue them. The terminology of devaluation has gained wide currency in the disability sector. It tends to relate primarily to people with disabilities, not so much their families. Family are not usually societally devalued and may even hold very valuable roles within the wider community. It might be difficult to devalue them in the same way people with disabilities are devalued.

Who demonises?

Broadly, we believe, there are two types of person involved in the demonisation process. Firstly there is the instigator and those others who know what is being done. These are the people who are "in the know". Part of the demonisation process for those the instigator is to show themselves as the good guys or the super ordinary people as a contrast to the evil or diabolic person who is the target of demonisation.

Secondly there are those who are not necessarily willing participants in the process and may not be aware that the process is occurring, but who are drawn in through their association with both the instigators and with the demonised person. This is the larger of the two groups without whose unknowing accommodation of the instigators intention the process of demonisation would be unlikely to accomplish the desired result, for there needs to be a large enough group to spread and legitimise the demonisation. It is likely that this large and unknowing group constitutes what might be described as the cement that sets the demonisation impetus into a concrete outcome. It is this group of people who are the key to the success or failure of demonisation and it is this group of people who can be alerted to the process that they are involved in.

In denial

"Denial has become the condition of our times" Cohen: 2001, p.47.

We are going to briefly outline some ideas associated with the concept of 'denial'. It may be useful in allowing us to accept denial as described as a common human behaviour and also explain why we are not aware of being demonised. Cohen lists many ways of denying. They include:

- 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 (Cohen, pp1-2)

In terms of denial Cohen asserts that there are three obvious possibilities. One, we did not know. Two, that we are lying and that we really did know and thirdly that we switched off or blocked out. Vietnam protests became very violent as the war progressed. When the soldiers returned home they were demonised as a tool of a bullying government. Then over some years nothing much was said but when the television programmes "China Beach" and "Tour of Duty" became popular veterans began to be rehabilitated. People forgot that the demonisation had occurred. They did not want to be reminded.

Just a little while back there was a round up of people on the east coast of New Zealand. They were arrested under the Terrorism Suppression Act. There were photographs in the newspapers and on television of armed police in their black combat gear checking vehicles at roadblocks. The simple fact of the event taking place, of mass arrests, of the terminology of terrorism being used widely within the media, allowed us to leap to the conclusion that this is another group of terrorists, and terrorists are a demonised group particularly in the western world. The actions were public.

We don't know what the covert reasoning for the action was. It may well have been that the police were simply testing the new amendment to the legislation, or it might be something else completely. But the use of the terminology of terrorism almost implies guilt before the trials begin. The process of demonisation begins with that language. Then some time later all charges under that Act are dropped. But in many minds those arrested are still demonised.

Cohen identifies that denial very commonly refers to the maintenance of social worlds where undesirable situations e.g. events, conditions, or phenomena go unrecognised, ignored, or made to appear normal and that people deceive themselves by lying, deluding and subjecting themselves to illusion.

Example of the process of one case of demonisation

The mother and father separated shortly after the birth of their child with a disability. The mother was and remains a solo parent. Therefore she has always relied upon a state benefit for existence. English is her second language and she has quite a lot of difficulty with it. It affects her understanding of concepts and processes. Though she has friends outside of her culture the people she tends to rely on are within it.

For many years there was acrimony between the parents over access to the child by the father. There were a number of occasions when this continuing battle brought them to court for resolution though nothing was ever properly resolved. Reports on her personality and her emotional state occurred because of the intervention of the court. At times she was described as depressed, emotionally unstable and obsessive. Nothing that services did was ever really good enough for her.

As with many parents of people with a disability this parent was known by the service sector and other related fields to be difficult to work with and was described as having a, “challenging personal manner with professionals”, or more politely as having, “an unusually intense personal manner”. The parent was “suspicious” of service agencies.

The mother brought her daughter up in her own culture, which entailed some practices that might be described as unusual, until one knows what they are for. This also seemed to bring about a racist reaction by some parties, and comments made by several of them have a distinctly racist overtone.

Some years ago, when the child became an adult, a welfare guardian was sought. The mother wished to take on that role. The father objected. A person who was known to the mother finally agreed. Over the next two years tension grew between the mother and the guardian. The guardian stated that she was very concerned about the behaviours of the mother towards her daughter. Two years after she became the welfare guardian the guardian removed the daughter from her mother’s day to day care.

The guardian had determined that the mother was mentally disturbed and a danger to her child. An opportunity arose for the guardian to remove the child and she did so. A friend of the mother’s went with her to the police to make a complaint about the actions of the guardian. The on duty constable rang the guardian. During that telephone conversation the police constable was told that the welfare guardian had a court order to uplift the child, that the mother intended to kill the child and then herself, and that she had a mental problem. The police took no further action.

The on duty constable did not question the validity of the information provided by a total stranger over the phone. The constable did not ask either the complainant or the mother’s friend if they had any disagreement with what he had heard. Yet there was no court order. The mother had never been diagnosed with a mental disorder and the threats to kill were a complete fabrication. It may be assumed that the on duty constable, having heard the comments about a court order, simply acceded to an authority with which he was familiar. It may well be that he put in a brief report to his superiors, though we have no confirmation of this. If he did it would have covered the conversation he had on the phone. He would have repeated the lies that he had heard. This is an important part of the demonisation process where ordinary people make stories solid.

Some months later access visits were begun for the mother. Very quickly she became frightened of the actions and attitudes of the service provider in whose care the guardian had placed her daughter. The mother requested a support person. The first few visits with a support person were amicable but then demands were made of the mother in relation to some of the unusual practices, e.g. the type of haircut, and, the checking of the daughter’s skin for health problems.

Within six months of removing the child the service providers and guardian, in official documents, e.g. needs assessments, were denigrating the mother, stating that she was acting strangely, that she had tried to kill her child and herself. Why was this information included in that document? Why did the assessor not check with the

mother or the support person regarding the accuracy of the information provided, particularly as they were not invited to the assessment? This type of easy acceptance of unsubstantiated negative statements, and of making them official by putting them in formal documents for all agency staff to see, like the police station incident, shows how easy it is for people to turn comments into accepted reality. As mentioned above these are the people who are the cement that makes the demonisation process concrete. How many other official communications exist and have added to the creation of a demon is unknown and are inaccessible to outside parties.

Then the support persons came under attack from the guardian and service provider for defending the actions of the mother. The guardian attempted to split the mother from the support persons by banning the support people from the normal place of access but inviting the mother to attend. The mother would not go to access visits without support and so other places needed to be found.

The refusal of the mother to go to access without support enabled the guardian to present this as evidence that mother didn't really care about her daughter. The guardian implied that they, the guardian and the service providers, were doing everything in their power to make for peaceful co-existence. The guardian introduced rules that outlawed the mother practicing any of the cultural and familial routines that she and her daughter had performed for over twenty years, with no detrimental effect to the daughter, practices that the daughter really enjoyed.

Access visits continued but became less frequent. The guardian and the service provider made it difficult for the mother during visits by imposing more authoritarian supervision and bringing in stricter rules thus making the visits more frustrating. Things said, and not said in the visits, were put to paper by the provider to make them official, concrete. This situation made the mother fearful of visiting and the visits became even less frequent until they were happening only once or twice a year.

The infrequency of the visits was again used by the service provider to demonstrate that the mother did not really want the child. Many letters were sent to the mother and to lawyers and other official agencies, and probably to other recipients of whom the mother is unaware, resulting in further publicising the inadequacies of the mother.

There were other letters that were sent by the service provider to the mother discussing her mental problems and the need for her to be seen to by professional medical people. Under continuing pressure the mother went to her own doctor and asked if the doctor thought she was mentally disordered. The doctor provided a letter stating how long the patient had been attending the practice and that there had never been any indication of mental disorder. And through all of this the guardian and the service providers continued to remind the mother that they loved her very much, that her daughter needed her, that as soon as she got herself together things would be fine again, and that she needed to trust them.

The mother did not trust them, and she continued to fight to get her child back. The main caregiver then wrote to the mother stating that she would not be involved in any more access visits because of the mother's behaviours towards them. The caregiver said, "I do not wish to be engaged in any ongoing communication with you...you continue to make allegations and cause disruptions...I have witnessed on several

occasions your emotional outbursts”. The threat of visits being discontinued through lack of compliance by the mother was not new.

The mother’s support team, because they were all she had, also came in for increasing criticism by the service provider. This situation was then used to prevent access visits since the mother would not attend without the support of that team.

The outcome

The result for the mother was that in the disability sector particularly she became ‘isolated’, ‘made powerless’, seen as ‘not credible’ or ‘untrustworthy’, ‘mentally disordered’ to some degree and ‘difficult’ to work with. The guardian, working in tandem with the service provider had the power to isolate and separate the mother from her child, and has put negative interpretations on the mother’s behaviour to present her as ‘mentally ill’ and ‘wanting to harm her daughter’.

The perceptions of previous agency workers of the mother as difficult/challenging were used by guardian and service provider to confirm and reinforce the negative perceptions of the mother, who viewed all of her actions negatively.

Her culture, English as a second language, and acrimonious child access issues have all been used in a negative way to bring about the demonisation of the mother. That demonisation process, occurring over many years, is extremely difficult to dispel.

This process has been going on at an intense level for some years, but was enabled by earlier decisions of courts and clinical reports which we are unable to publish.

In Summary

Demonisation in one form or another has the intention of marginalising a person or a group of people and of delegitimising their viewpoints. It does this by constructing an image of them as evil with the intention of bringing about a situation where no response is required to any assertions made by the demonised. As previously mentioned there is very little that we can find which relates to this process in the disability sector but we believe that it does happen and is not uncommon. However we believe that it is difficult to track the process since it is usually covert.

This conference is about Trusting Partnerships. Trusting Partnerships we believe require an equality of influence, an acceptance of different viewpoints and an understanding of the needs of the various parties to any partnership. This necessitates an openness which is not, by and large, evident to us in the area in which we work.

Additionally there are some very valuable things which get lost when demonisation occurs. One example is that valuable information is lost because the person who has been demonised may know the person with the disability better than any other person alive, particularly if it is the mother, father, sibling or long term advocate or friend. That information may provide keys to particular behaviours or needs of the person, and which may have been learned by the demonised person over a long period of time.

The history of the person with the disability, which may be vital for the caregivers to know and which may not be written down, may be lost if there is no acknowledgement of the input if the person bringing that knowledge to the caregivers has been demonised.

To bring about Trusting Partnerships there must be an acknowledgement by those who wield the power, i.e. the funding agencies, the service providers and the state agencies, that there is a huge imbalance of power. They must voluntarily relinquish some of it to the families and to the person with the disability.

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