August 2012

2222

A CASE STUDY - CONTROL, THREATS AND INTIMIDATION IN DISABILITY SERVICES IN VICTORIA

Authors: Margaret Ryan & Max Jackson –

Synopsis

This paper demonstrates how guardianship is being used as a tool in the disability sector to control, threaten and intimidate parents and effectively abuse the rights of persons with a disability.

The Players

The case involves a single mum, her 37-year-old daughter with an intellectual disability, a funded residential service, a funded advocacy service, the Disability Services Commissioner (DSC), the Office of the Public Advocate (OPA) and the Victorian Civil and Administrative Tribunal (VCAT).

Setting the Scene

The daughter, who for the purpose of this paper we will call Emma, lived with, and was supported by her mother for the first thirty years of her life. This situation was one of mutual respect and what might be described as a normal loving mother-daughter relationship. In order to allow Emma the opportunity to live with other people of a similar age and effectively live in her "own" home, mother and daughter mutually agreed that Emma should move into a funded residential service. Thus, from 2004 until mid-2012 this is what occurred.

While generally Emma enjoyed the experience of shared supported accommodation, unfortunately particular staff in Emma's house failed to provide the level of duty of care required. Thus, Emma's mum, who had been meticulous in the care of her daughter and who had worked hard to develop Emma's social skills and facilitate Emma's community inclusion, expressed her concern to the staff when issues arose in relation to her daughter's health care and other matters to do with her daughter's wellbeing. Concerns such as the failure of the service provider to protect Emma from ongoing physical abuse from another resident, non-compliance with prescribed dietary requirements and failure to promote a recommended and prescribed exercise program.

Emma's mum also expressed concerns at a lack of support in ensuring an adequate fluid intake to counter a significant medical condition, a failure to support necessary skin care, a lack of support to facilitate self-help skills such as clothes washing.

Although Emma's mother showed a willingness to work with the staff in order to address the service and support deficiencies and various remedial strategies were agreed, the failure of the support staff to meet their duty of care responsibilities continued. When the mother pushed harder for a fair deal for her daughter, the staff resistance increased.

When Emma's mum continued to challenge and exhort the organisation to ensure improvement, staff then applied subtle pressure on Emma to challenge her mum's involvement.
Emma's mum's willingness to work with senior management proved fruitless, and indeed mum was cast as the villain by the Chief Executive Officer (CEO), who demonstrated what might be described as "blind loyalty" to his staff, despite the evidence of some staff failing in their duty of care. It was also at this time that the CEO made a veiled threat that guardianship was an option.

The rub finally came early in 2012 when a representative of a funded advocacy organisation became involved. While the advocate initially judged Emma as able to make her own decisions, Emma's decision to move back to her mum's home was the catalyst for a Guardianship application being made by the advocate to VCAT.

> *From then, until the application was withdrawn in August 2012, the so-called support system became the enemy of both Emma and her mum.*

The support system became an enemy that was hell bent on splitting a loving family relationship. An enemy, whose sense of righteousness and sense of self-importance caused the disability agency to ignore the deficits of their service and to use guardianship as a threat, and a paid advocate whose failure to understand the nuances of family relationships caused him to make a guardianship application that overrode the rights of a person with a disability and her mother.

The Dark Side of Disability Support and Advocacy

Despite the legislation, the myriad of principles, the promotion of rights and the ideal of self-directed decision-making and choice, this case demonstrates how power and intimidation can be unfairly wielded when the system is challenged.

Emma's mother rightly questioned staff about their failure to adhere to service improvement agreements, to follow health professionals' instructions, and their inconsistency in addressing Emma's needs. Initially, staff showed a pretence of concern and suggested even more meetings. Then, when the deficits continued, they began to use the catch phrase that "Emma had exercised her choice". This was code, for example, that it was Emma's choice to not adhere to her diet, it was Emma's choice to not participate in her prescribed exercise program, and it was Emma's choice to not maintain good hygiene. However, despite more meetings, more plans and more checklists the service and support deficits continued.

Emma's mother continued to exercise her right to advocate on behalf of Emma (who, by the way, had provided her authority for her mother to do so). Despite the advocacy being pursued over a period of some seven or so years through a succession of meetings with various levels of management, the deficits continued.

In the first instance there was a group of staff who failed in their duty of care to Emma, but then sought to roadblock a concerned mother by manipulating the client into saying she did not want her mother involved. This was a completely contradictory position to one previously expressed by Emma and was inexplicable, unless resulting from staff intervention and manipulation. This was an intervention aimed at diverting attention from the mother's challenges to the service deficits, and thus seeking to effectively freeze the mother out. Inherent in this was the intended threat to convey to Emma's mum that if her daughter didn't want her involved, the staff could "legitimately" stop the mother from visiting her daughter's home and her day placement.

The staff's manipulation went beyond this, however, in that they then deliberately changed Emma's medical appointment as an attempt to ensure that Emma's mother did not attend the appointment. This action was taken by the staff despite a previous agreement between the agency and Emma's mum that she would take Emma to her health professional appointments. Attending the appointments enabled Emma's mum to follow up on matters concerning Emma's medical care, an area where there had been concerning deficits. Although Emma had stated that she did not want her mother involved, thus changing her mind from her previous position, this was not only an indication that Emma was confused, but further it demonstrated that the manipulation of Emma by staff was complete. In other words, surreptitiously the staff actions intimidated Emma and thus sought to control the mother.

There was then the involvement of successive levels of management, culminating with the involvement of the CEO. Each level of management not only failed to acknowledge the possibility that some staff may well have failed in their duty of care; but, just as concerning, if not more so, management failed to thoroughly investigate the claims made by Emma's mother.

It was at a meeting with the then CEO of the service organisation in mid-2011 that the ugly-side of disability support and advocacy really exposed itself.

The CEO committed an even greater failure in that he not only demonstrated a condescending attitude towards the mother and challenged the attendance of a support person at a meeting, but he then sought to turn the mother's concerns into a blame game against her. The final ignominy committed by the CEO was his condescending suggestion that if the mother was not satisfied she could seek guardianship through VCAT. Knowing full well that the history of guardianship applications by family members is that more often than not these have been met with refusal; and also knowing full well that guardianship provides no more power over an organisation than does a family member without the authority of guardianship.

In an attempt to have her concerns taken seriously, Emma's mother had taken the matter to the Disability Services Commissioner, and mediation was undertaken. The CEO was fully aware of mediated outcomes that had been negotiated between Emma's mother and representatives of the organisation through the Disability Services Commissioner. However, these outcomes had not been fully implemented by the organisation. It was this failure that had been the catalyst for seeking the meeting with the CEO. And yet, the CEO at the meeting with Emma's mother effectively ignored the fact that the outcomes as agreed through the Commissioner had not been fully implemented.

Fast-forward 12 months. Out of the blue Emma says she does not want her mother involved. Enter a representative of the funded advocacy organisation.

Without seeking to engage Emma's mother, after only three or four cursory meetings with Emma, without engaging Emma's day service, and without seeking to investigate why Emma would suddenly change her mind about her mother's involvement after a life-long loving and supporting relationship, a guardianship application was submitted to VCAT. Why?

It can only be surmised that the very staff who had been challenged by Emma's mother were consulted by the advocate and it was their subjective and biased view, and their obvious intent on self-preservation, that was accepted by the advocate without question.

The fact that the advocate's application was ill-advised, lacked substance and was considered as wrong, is evidenced by the fact that as the result of an investigation by an OPA representative, OPA advised that they would challenge the application if it went ahead. The advocate did not of course stand alone in making the application as his CEO confirmed it as appropriate.

In making his application the advocate not only failed to speak with Emma about his intended action, but he then also failed to advise her of his intention to withdraw it. However, of even greater concern was what can only be described as the use of 'bully-boy' type tactics by the advocate, to obtain information from Emma's doctor without ever advising Emma or seeking her authority to do so. The advocate also ignored the principles enshrined in the Disability Act 2006 concerning the significance of family; and further he also ignored the principles as detailed in his own agency's policy and guidelines concerning individual advocacy.

In essence, the advocate allowed his ego and perceived authority to ride roughshod over Emma and her mother.

The involvement of the OPA, at the request of VCAT, was a godsend in that the OPA investigator soon determined that the guardianship application was not based on any substantiation, that it ignored the strong bond between mother and daughter, and was in essence fallacious and ill-considered. And, it was clearly because of the OPA report that the advocate withdrew his application.

While the role and actions of VCAT were in accord with the published guidelines, nonetheless this case highlights a number of deficits, which have also been highlighted by the Law Reform Commission in their final Report into Guardianship.

The Abuse of Language and Intent in Disability

Five significant situations evident in this case highlight how what might be termed 'the language of disability' and the power invested in particular individuals and entities can be misused, or constrained by inadequate legislation leading to ineffective policy and processes.

The first situation relates to the way in which funded service providers monitor their service provision and what they do in the event of service deficits arising. In this case, significant service deficits arose over a period of some seven to eight years. They were brought to the attention of staff and management and the mother of the client did participate positively in seeking to have the problems rectified. Despite this, the problems persisted and staff continued to fail in their duty of care while management gave lip service to addressing the problems.

Essentially the organisation failed to fully acknowledge and put into practice the principles as contained in the legislation as well as the values as expressed by their own organisation.

Yet, when it suited, the organisation espoused Emma's right to choose and shifted the responsibility to Emma by in effect suggesting that it was her own actions and decisions that created the deficits, and not the failings of the staff.

The second situation relates to how the then CEO of the organisation not only failed to thoroughly investigate the mother's concerns and the failure of his staff to meet their duty of care to Emma, but then cast the mother as the villain in the story. When the challenge was put to him to fix up the service provision, he chose to espouse the option of guardianship. Additionally, the CEO also failed to ensure the implementation of the agreement arising from the mediation conducted by the Disability Service Commissioner's office 12 months prior. Further, the CEO then ignored the request of the mother to be interviewed by the auditors contracted to conduct a quality audit, using the excuse that this could not be done because those to be interviewed could only be randomly selected.

The third situation relates to the involvement of an advocate employed by a funded advocacy service. Like a bull in a china shop this person entered the fray. He failed to investigate and take full account of all of the facts, ignored Emma's right to make a decision to return to the family home, despite the fact that the advocate had previously assessed Emma as being capable of making and understanding her own decisions. He then totally ignored Emma by not informing her of his intent to submit a guardianship application, by not seeking her approval to request information from her doctor, and not informing her that the application was subsequently withdrawn.

This advocate, while using the language of disability in terms of a client's right to self-determination and to be involved in decisions, acted contrary to these sentiments. He also ignored the principles of the Disability Act and the values expressed by his own organisation.

The fourth situation relates to the funded advocacy service. When the mother contacted the CEO regarding the actions of his employee, the CEO gave scant attention to the issues and instead categorically supported the guardianship application.

In so doing he also totally ignored the principles of the Disability Act and the values expressed by his organisation, and instead displayed "blind loyalty" to the staff person. The organisation through its CEO displayed little or no understanding how the rights and welfare of a person with a disability can be very much tied to the notion of family unity, as evidenced by the fact that Emma had made the decision to return to the family home before the application for guardianship was made. Logic therefore suggests that in a case such as this the responsibility of the organisation is to both the person with a disability and the family. In this case the organisation denied both Emma and her mother the right to maintain family unity.

The fifth situation relates to the role of VCAT. In this case clearly VCAT met the demands of the legislation which governs it and the processes arising from this legislation. However, what this case has demonstrated is how an entity such as VCAT can be constrained by inadequate legislation which then leads to ineffective policy and processes. In other words, although there is no doubt that VCAT would wish to facilitate the principles as espoused in the Disability Act 2006, the fact that the guardianship legislation allows anyone to make a guardianship application, and allows the application to be heard without the requirement to assess its merits prior to listing for hearing, demonstrate that currently VCAT's hands are somewhat tied.

The issue arising out of this case is not a questioning of whether VCAT did its job, but one that raises the issue of the importance of some of the Law Reform Commission's recommendations on guardianship.

A Need for Justice

This case highlights, without any ambiguity whatsoever, that the protections of the rights of persons with disabilities and their families, the same protections that were so enthusiastically promoted, are open to abuse and manipulation. This case also highlights the need to make changes that impose a greater responsibility on the many players who like to promote themselves as the flag-bearers for disability rights.

The following five actions are essential to stamp out control, threat and intimidations as currently practised in the disability sector.

1. The provision of funded advocacy support for families

Although advocated for many years, successive governments have ignored the need for families to be able to seek the support of a funded service specifically dedicated to representing families. Families have been left to their own devices and are in effect thrown to the wolves in having to advocate and 'take on' the power of service providers, and funded advocacy services that do not consider their interests as a component of advocacy.

Until or unless, governments are willing to show real support for families of persons with disabilities by funding family advocacy, the principles in the Disability Act 2006 as concerning families will simply remain empty sentiments.

2. The case for real authority to be legislated to the Disability Services Commissioner

While the establishment of the Disability Services Commissioner position constituted a major step in reviewing complaints, the fact is that without the legislative authority to compel or direct, the role will simply remain dependent on mediating outcomes. Although mediation is a useful tool in dealing with disputes, it does not always provide the answer. Where an agency refuses, as evidenced in this case study, to abide by the outcomes of mediation, the family and the person with a disability remain powerless.

Thus, the current government must show the courage to amend the Disability Act 2006 and legislate to give the Disability Services Commissioner the authority to exercise real power.

3. The case for greater scrutiny and accountability of funded service agencies

Despite the requirements detailed in Funding and Service Agreements with the Department of Human Services (DHS) and the relatively recent introduction of Quality Audits, the reality is that time and time again we hear of situations arising in funded agencies whereby the agency has clearly failed to uphold both the letter and intent of legislation as well as their own documented intent.

What this highlights is the urgent need for even greater scrutiny and accountability to be imposed. In part this requires the government, through DHS, to adopt a far more stringent approach to monitoring service agencies. In part it is also linked to the suggestion above that the Disability Act 2006 be amended to give real power to the Disability Services Commissioner whereby through investigations undertaken by the Commissioner's office, the Commissioner would then have the power to direct any necessary changes.

The current system has failed to ensure that service providers live up to the intent and the letter of the legislation.

Therefore, it is clear that unless or until such time that the results of the recently introduced quality audits are made public, then funded and contracted agencies will be able to continue to hide behind the veil of secrecy.

As such, this paper therefore calls upon the government to make public on an annual basis the results of quality audits undertaken of funded and contracted agencies.

4. The case for greater scrutiny and accountability of funded advocacy services

Funded advocacy for persons with disabilities has now been in operation for some thirty or so years. While advocacy for persons with disabilities is a highly desirable and necessary service, there is little evidence to suggest that successive governments in this State have ever undertaken a detailed evaluation of funded advocacy services in order to ensure their accountability.

Indeed, the longevity of some of the funded advocacy agencies seems to have given them a status of being a "sacred cow" and therefore untouchable.

Despite the introduction of quality standards for funded advocacy agencies through the federal sphere, there is no evidence to show that quality standards actually produce a better quality service.

While recent amendments to the Disability Act 2006 now allow for complaints about advocacy organisations to be made to the Disability Services Commissioner, nonetheless the point as made further above as to the Commissioner not having any directive powers weakens this provision.

This case clearly demonstrates that not only did the advocacy service initially through one of its employees, and then supported by its CEO, fail to uphold the rights of Emma, their actions actually sought to undermine a positive family relationship and excluded not only the mother but the client from being informed of the advocate's intention.

As detailed above, the advocate transgressed many principles and based his actions and decisions on minimal information and his own sense of self-righteousness.

The time has now come whereby the Government must introduce greater scrutiny of funded agencies and demand their total accountability to persons with a disability, their families and the public.

The Government must ensure that funding rounds for the provision of such services are not a foregone conclusion simply by funding an agency because it has been funded before.

5. The case for modifying the process of vetting applications for guardianship

The current legislation and procedures relating to the operation of VCAT are restrictive. As evidenced by this case, VCAT is required to accept an application for guardianship just so long as the required "paperwork" has been provided. In this case, the applicant went beyond the requirement to provide medical certification of Emma's intellectual disability and instead used coercive power with Emma's doctor to gain supporting evidence for his case. Despite this, VCAT provided no advice to Emma and denied her mother access as to what information had been provided via the applicant by Emma's doctor.

The fact that the current legislation allows any person to submit a guardianship application opens the way for an abuse of this provision. Indeed, in this case this was what happened. As such, this paper supports the recommendation in the Law Reform Commission's Final Report into Guardianship (Recommendation 348, page 486) and paragraph 21.11.0, that before accepting an application for guardianship "an analysis of the application to determine whether it should proceed directly to hearing or be referred to an alternative process" should be enacted.

Additionally, this paper supports Recommendation 350, page 487, of the Law Reform Commission report, that it should be VCAT who makes "a preliminary determination of the potential parties to the proceedings and people entitled to notice." The current arrangements provide for the applicant to notify potential parties. In this case the applicant clearly chose not to notify all interested parties including a representative from Emma's day service.

The current deficits in relation to the rules relating to VCAT's authority and processes must be addressed as quickly as possible in order to avoid ill-informed and high-handed attitudes as demonstrated by the applicant in this case.

Concluding comment

This case study clearly demonstrates that, despite the self-congratulatory rhetoric which abounds in Victoria concerning how 'we' are leading the field in Australia in the disability sector, not all is well in the sector.

It is not good enough to constantly make pronouncements about rights, sing the praises of standards and quality audits, establish a myriad of plans and promote the National Disability Insurance Scheme and individual funding as a panacea for the future.

Even in a situation of individual funding, where it might be argued that if a person is dissatisfied with a service the person can take their money and seek to be supported through another service, this can hardly be considered as an argument for the status quo, where the status quo means an inferior service or one where bullying or intimidation are allowed to blossom, continues to be funded and is approved to operate.

The real challenge in this case is to either force such services to change or refuse to approve them as disability service providers. It is time that a much stronger approach is taken, and rather than just mouth the words of quality, that the primary controller, as in the government, tackles the hard issues. The current situation of what might be described as a "buddy-buddy" system does not provide a sound basis for building quality services.

As long as individuals and entities within the system are allowed to continually bypass their responsibilities by using their power and position to threaten and intimidate, persons with disabilities and their families will continue to remain at the bottom of the pile in terms of the hierarchy of control, power and influence.

About the Authors

Margaret Ryan and Max Jackson operate a boutique consultancy – JacksonRyan Partners - that specialises in workplace relations as well as policy and practices in the disability sector.