

GUARDIANSHIP AND ADMINISTRATION BOARD
HOBART

MW on application by SJW

GAB No.

REASONS FOR DECISION

Anita Smith (President)
John de Jong (Member)
Marguerite Lester (Member)

Guardianship – capacity – overly protective and restrictive parents – need for independence and broader social interaction – complex medical conditions – least restrictive alternative – lack of compatibility with proposed guardian – role of Disability Services in family dispute
Guardianship and Administration Act 1995 (Tas), ss 6, 19, 20, 21 and 50

1. Pursuant to section 19(1) and 50(1) of the *Guardianship and Administration Act* 1995 (“the Act”) the applicant has applied to the Guardianship and Administration Board (“the Board”) to be appointed as the guardian and administrator for her daughter, MW. M is a 20-year-old woman who presented with a disability in the form of a borderline or mild intellectual disability, and a further disability that compromises MW’s physical health and her vision.
2. The application was lodged with the Board on 14 February 2003. The application was heard in three sittings on 17 April, 16 May and 10 October 2003. Counsel represented Mr and Mrs W at all sittings. Counsel represented M at the latter two hearing dates.
3. The application was opposed by M, her support staff and staff from Disability Services. At the second and third hearings counsel for M informed the Board that the application for administration was not opposed. On the basis of evidence presented, the Board made an order appointing the Public Trustee as administrator for a period of 3 years. The Board was satisfied that selection of the Public Trustee as administrator reflected M’s wishes and the least restrictive alternative as well as being in her best interests.

4. There was no dispute about the presence of a disability. There was dispute about the effect of that disability upon M's ability to make reasonable judgments in respect of her person and circumstances and whether there was a need for a guardian.
5. M's wishes, for the purposes of section 6(c) and 21(2)(a), were clearly stated by herself and her counsel to the effect that she did not want any guardianship order and, if there were a guardianship order, she did not want her parents appointed. The interpretation of principles in section 6(a) and (b) were central to the reception of the evidence presented.

The history of the application

6. M has lived with her parents and 2 siblings in a small remote community since birth. Between the ages of 14 and 17 years, she boarded in Interstate to receive education at X House, a service organisation that provides specialist education to blind and vision impaired children. When she finished that schooling she returned to live with her parents in the family home. The evidence suggests that M's parents provided her with an excellent childhood and a very supportive environment where they encouraged her to develop and succeed to the best of their abilities and resources.
7. The Board received written testimonials from members of the small community. Several witnesses, including the applicant and her husband, provided evidence of a strong and loving family environment. However, evidence also suggested that the family relationships have broken down since the start of 2003, and possibly earlier.
8. In 2002, community advocate, CJ attended that community and met M at a day care centre. Although their discussion was short, M told CJ that she wished to leave the

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small community. CJ subsequently had a brief discussion with the relevant members of Disability Services but she took the matter no further at that stage. Disability Services record their first contact with M on 23 October 2002. Disability Services had provided some respite services for M between October 2002 and February 2003.

9. On 3 February 2003, M attended a hairdresser and had her hair cut in a manner markedly different to earlier hairstyles. M's mother did not approve of the haircut. On the 6 February 2003, M sent an email to a staff member of Disability Services explaining that her mother had yelled at her and hit her because of the haircut. The email includes a photograph where M displays a bruise on her arm allegedly linked to her mother hitting her with a hairbrush.
10. The evidence of the assault and the bruise are disputed by the applicant. In any event, the incident brought to a head M's desire to leave home, which she communicated to Disability Services staff. When the email was sent, M was staying with LD who was paid by M's parents as a carer. M's parents were away camping overnight.
11. Disability Services staff then assisted M to leave the small community while her parents were away camping and without their knowledge. There was no evidence that M's parents were ever warned on M's desire to leave that community or her intention to do so. She arrived in the city on 7 February 2003 and initially stayed at the respite service. M's mother then withdrew a substantial amount of money from M's bank account. She stated that this was to prevent financial abuse should M be under pressure from new associates. It was later deposited back into the account after the intervention by the Police.
12. From February 2003, M's parents have expressed their continuous wish to have M return home with them. By contrast, she has expressed a desire not to return home,

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and to have no contact with her parents for the time being. M was, by the third sitting, established in a single unit in the city within a supported complex for people with disabilities managed by M Service. She attends TAFE, has support from Family Based Care and attends Special Olympics training and church.

13. The relationship breakdown between M and her parents is quite profound. M has gone to the extent of having a solicitor from the Legal Aid Commission write to her parents threatening a restraint order if they did not cease attempts to contact her. However, M provided notes to the Board which discussed restoring her relationship with her parents at some later time.
14. There was dispute about M's recent lifestyle in the small community. Counsel for the applicant stressed need for protection for M and provided evidence of the appropriateness of her parents care to date. Counsel for M provided evidence of a limited lifestyle, overprotection and excessive control by the parents.

The medical evidence of disability

15. The result of M's disabilities is underdevelopment of the optic nerves and a number of hormonal deficiencies. These relate to underdevelopment in the hypothalamus and the pituitary gland. If M becomes unwell, she may be vulnerable to potentially fatal adrenal crises. M also has epilepsy which according to the evidence is presently is well controlled. She has extremely limited visual perception.
16. The Board received evidence that M had experienced 2 adrenal crises in her life. Each time her parents were close by and able to seek immediate help and avert dangerous consequences. There was no dispute about the parent's evidence that on each occasion M was unable to seek assistance herself, and required the competent intervention of another person.

17. M takes a range of medications to control her epilepsy and to address the hormone deficiency. There was evidence that she is compliant and responsible with the medication regime. Evidence submitted to the Board included historical written advice from doctors to institutions, such as the interstate school, about the appropriate management of the conditions.
18. Serious potential risks to M's health include failure to ingest medication (through forgetting, vomiting or diarrhea) and excessive weight gain. In a letter dated 19 June 2001, Dr C states that M "... requires special care otherwise she may experience an adrenal crisis, which is an extremely serious condition." Dr C further states that: "If M is unable to take her cortisone tablets orally due to vomiting, or she is significantly unwell, she should immediately have a parenteral injection of glucocorticoid (example 100 mg hydrocortisone) with careful ongoing medical supervision."
19. The applicants' case was that M's condition presents risks so serious that her parents are the only people who can responsibly and competently manage her health in the short or long term. M's case was that she is managing and will continue to manage her condition responsibly and competently.

The evidence relating to the question of capacity to make decisions

20. The application was accompanied by a Health Care Professional Report by Dr RN. He stated that M has a 'permanent intellectual disability'. He believed her capacity for new learning to be limited and cited, as an example of her planning and reasoning ability, her decision to move to the city without essential medication. Later evidence confirmed that M did take all necessary medication with her. Dr RN's assessment of M's level of intellectual capacity is lower than all other assessments of her intellectual capacity.

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21. In response to the application, Disability Services provided a report by AW, psychologist. AW reported that M “will be capable of articulating many of her needs, and making various decisions independently or with minimal support.” AW cautioned that M will experience a degree of difficulty in fully comprehending complex information. AW’s report was useful in exploring the manner of M’s decision making. She concludes that “... M has the intellectual ability to make independent choices, and to acquire the skills necessary to have a level of autonomy.”
22. At the conclusion of the first sitting the Board determined that the specific question of M’s capacity to understand her particular health condition required further investigation. Accordingly it made an order for the Public Guardian to arrange medical reports that addressed this issue.
23. The Board then received a report from Clinical Neuropsychologist, DA. Dr DA found that M functions within the borderline level of general intellectual abilities with similar performance in language and construction skills. He made recommendations about the need for an administrator because of M’s lack of capacity in financial matters. He expressed caution about M living independently, preferring supervision. He then stated: “However, if this is unlikely, then I see no reason why she should not remain in her present situation with the proviso that her guardian monitor her situation and request a review if there is some concern for her well being.”
24. Associate Professor CK, Neurologist also reported to the Board. She concluded that M requires a degree of supervision to ensure that she takes her medication regularly and appropriately.

25. Dr C, M's treating endocrinologist, said "I asked M about her knowledge of 'sick day' management. She was unsure what to do if she was mildly unwell but knew to 'press the buzzer' if significantly unwell." Dr C's main concern was M's recent weight gain.
26. Prior to the third hearing date, the Board received a report from Dr DS. Dr DS also attended by telephone at the third hearing. She stated that M appears to take her medications and has an understanding of their necessity. In contrast to the specialists, Dr DS did not place M's potential for weight gain as more serious than it is for any member of the community.
27. The Board had evidence of two occasions where M addressed her own medical condition since living independently. On both occasions M sought admission to hospital to be observed until risks had been assessed and symptoms had passed. To her credit, M has been competent in accessing health services to date.
28. The Board took the view that the effect of M's multiple disabilities upon her capacity to make certain lifestyle and health care decisions is cumulative. Therefore, while the level of intellectual disability would not normally be sufficient for the purposes of a guardianship application, the complexity of the other health conditions was such as to make her incapable of undertaking certain complex decisions required for their adequate long-term management.

The evidence relating to a need for a guardian

29. The applicant submitted that M required a plenary guardian to monitor her diet, exercise regime, accommodation choices and medical treatment. They placed emphasis upon her physical disabilities and the potential for adrenal crisis. When asked of her plans for M if granted guardianship, the applicant stated she would "try and exercise her and get the weight back off her."

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30. Despite grave fears on the part of M's parents, M made very positive developmental gains since moving to the city. Evidence from advocates and support workers indicated that she had acquired life skills such as cooking and cleaning in the eight months since she left home. She has also involved herself in a range of activities, church and community groups all of which appeared age appropriate. Her financial skills, however, remained poor prompting support for the application for administration.
31. Counsel for the applicants suggested that evidence from witnesses that she had mouldy food in her unit on one occasion and a broken bed for a week was evidence that her living skills were not as good as suggested. The Board took the view that these two examples did not demonstrate a consistent pattern and were not unlike living conditions found in accommodation for people of a similar age, for example: university students.
32. It was also submitted that M's recent weight gain established a need for a guardian. The Board took the view that while weight gain is a serious matter, and a live-in guardian would have the ability to closely supervise M's exercise regime and diet, such a measure would be a last resort. Other measures can be attempted to increase M's opportunities for exercise and monitor her diet without requiring her to return to the daily supervision of her parents.
33. The fundamental inconsistency in the applicant's case was that on one hand they stated that M's condition was dangerous and required daily supervision by parents, implying that no other person could competently manage M's health. However, on the other hand, there was evidence that as a much younger person M had boarded away from home for extended periods and those who boarded her were able to follow simple medical instructions that had kept her from serious harm. Additionally, M's parents were camping overnight at the time of her leaving and

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had left M under the supervision of a person whom they paid \$5.00 per hour. At that rate, the Board concludes that this was not professional care and that even M's parents did not believe she needed 24-hour professional supervision in the absence of her parents at that time.

34. The Board accepts that the parents were overly protective and restrictive in their care of M. In their efforts to preserve the support available to her from the family, the parents failed to fully recognize M's developmental needs for independence and broader social interaction. The Board heard evidence of a range of services that presently provide activities and support to M for a large part of each day, except Saturdays and Sundays when she has one hour of structured support. The evidence of some members of the team who support M's independent living showed a poor understanding of her condition and its management.
35. The Board concluded that M is a person with a disability, and that her capacity to make lifestyle decisions is generally good and improving with greater independence. However, her medical condition presents some complexities and the need to establish systems for those who support her to understand and address potential problems. In the event of an adrenal crisis she may be rendered unconscious. Therefore comprehensive support strategies need to be in place to assist her in an emergency situation and to avoid adrenal crises. Her capacity to establish those systems is limited and a need exists to that extent.
36. The Board rejected the notion that M needs a guardian for all areas of her life.

What is the least restrictive alternative?

37. Obviously, the least restrictive alternative in this case would be to appoint no guardian at all. This would leave M in control of all decisions about the level of her support and medical attention. The Board considered that this left a risk that the

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long term management of her medical condition and establishment of appropriate support systems might be overlooked. Accordingly, the Board found that the least restrictive alternative, which would also take into account her best interests, is the appointment of a limited guardian who can ensure that regimes are established which ensure that regular assessments are adhered to and that staff and support people are adequately trained in emergency responses and long term care for M's medical condition.

38. When M lived with her parents, her life was almost completely controlled, as well as completely funded, by her parents. Her living skills and capacity for independence were limited. Some of the limitation existed because of limited activities for young people in the small community. It is clear that if the parents were appointed as plenary guardians, they would hope to resume that very close level of supervision and control which had existed prior to M's move to the city.
39. M's 19-year-old sister, KW was at pains to support her parent's application but some comments reflect family attitudes that are particularly restrictive:
40. "It is great for M to have such a positive outlook on life, and have such determination to do things on her own in Tassie. However, after growing up with M I know that she is not capable of looking after herself properly, and there are certain things she will never be able to do because of her health. ... Since she has been living in the city these last couple of months, I have really noticed a change in her attitude and behaviour. She believes she can do everything on her own now and doesn't need mum and dad to help her. But this is not the case because mum and dad know her better than anyone else could, and I know her as my sister and there are certain things that she cannot do on her own and she never will be able to."
41. Clearly, M's departure from the small community has caused the W family and members of their community distress. KW's statements echoed a number of

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statements by M's parents and their associates from the community which were benevolent and demonstrated affection but did not promote adulthood, independence, freedom of action or decision for M.

42. The Board took the view that appointing M's parents as guardians would be a particularly restrictive alternative.

Who is the appropriate guardian?

43. M's parents asserted that they were the most appropriate guardians on the basis of their intimate knowledge of M, previous history, family closeness and their record as good parents. It is arguable that they were eligible for the purposes of section 21(1), however they were not suitable for the purposes of section 21(2).
44. M's wishes, for the purposes of section 21(2)(a), that she did not want her parents appointed as guardians were clear and consistent.
45. The Board took into account section 21(2)(b). At the time of the final sitting, the family relationships are at their lowest ebb to date. An order appointing the parents as guardians would not have the effect of restoring family relationships when they have broken down to such a considerable extent.
46. For the purposes of section 21(2)(c), the Board cannot assume any compatibility between M and her parents. Given the level of conflict between M and her parents displayed at the hearings and in correspondence, it would not be appropriate to appoint M's parents as guardians. Central to the incompatibility was a lack of acceptance by M's parents of her transition from adolescence to adulthood.
47. The Board took the view that a guardian is only necessary for the limited purposes of establishing certain regimes and ensuring a required level of care related to her

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accommodation and health care as specified in the order. Accordingly, the Public Guardian will be suitably available and accessible for the purposes of negotiating the necessary training and development of support staff and section 21(2)(d).

The role of Disability Services in the history and the application

48. The Board formed a view that limited guardianship is now necessary in part because of the fragmentation of family relationships, and notes further that the parents might not have made the application had Disability Services intervened in a manner more conducive to the preservation of these primary relationships. The process of this application had the effect of making divisions between Mr and Mrs W and their daughter greater. Certain evidence was demonstrably painful to all parties.
49. According to written evidence from Disability Services, M's desire to leave the small community was first made known to them on 6 February 2003 in an email to a staff member. Staff of Disability Services then supported her almost immediate departure from that community.
50. Evidence from Disability Services stated that they did not encourage M to engage in a discussion with her parents prior to leaving because:
- (i) She was afraid that her family might stop her from leaving,
 - (ii) She had a right to privacy and confidentiality, and
 - (iii) M has requested that Disability Services not make contact.
51. It is not apparent from any evidence that staff from Disability Services seriously attempted mediation between M and her parents before her departure or even shortly after. It does not appear that any mediation services were suggested or

offered until Mrs W traveled to the city some weeks later. Staff members have consistently refused access to any information about M to her parents.

52. It is acknowledged by the Board that M is an adult and capable of making most lifestyle decisions. She, however, is still a young and impressionable adult. Apart from one disputed incident, the evidence suggested that she had lived safely with her parents for a long period prior to 6 February 2003. It is not suggested that the secrecy was necessary for her personal safety. Further, the evidence suggested that Disability Services failed to adequately take into account the seriousness of M's health condition prior to the move. Overall, the evidence suggested that Disability Services overlooked the severity of M's health condition in their efforts to actualise her developmental potential.
53. It is entirely possible that had the staff members at Disability Services suggested that M stay with LD, or some other supportive person in that community, until a mediation session had been arranged that M may have made a slower but more peaceful and successful transition to living independently in the city with the parental relationship intact.
54. The Board considered that Disability Services staff actions in assisting M's departure from the community on scarce evidence or information and without consultation with her parents has contributed significantly to the fragmentation of the relationship between M and her parents. Their subsequent refusal to provide any information has contributed to M's parents' increasingly frustrated attempts to make contact and some of their emotional outbursts during the hearing process.
55. The Board does not suggest that Disability Services does not owe a duty of privacy to its clients. It does however appear that in this case Disability Services staff have not acted in the best interests of M by allowing the family division to escalate to the point of threats of restraint orders when an approach by a neutral party at an early

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date may have facilitated better flow of communication and more understanding by Mr and Mrs W of their daughter's decision to be more independent.

56. It was clear in the hearings that Disability Services staff had exclusively provided counsel for M with statements, witnesses and file notes which they had not provided to counsel for Mr and Mrs W prior to tendering. There was no visible attempt by Disability Services staff to balance the responsibilities expected of a publicly funded service to be a 'model litigant' against its duty of privacy to M. Such behaviour entrenched Mr and Mrs W's feelings of alienation from their daughter and assisted the hearing's unusually adversarial nature.
57. The Board takes the view that it is in M's best interests that the relationship between her and her parents is restored. The inhibited flow of information between Disability Services and M's parents has very serious implications for the appropriate exercise of a duty of care over a woman with such complicated health conditions. Fortunately, there have been no serious health complications since M has taken up residence in the city. However, an appropriate discharge of a duty of care would suggest that cordial and informative relationships regarding M's health status must be reestablished between M, her parents and support persons as soon as possible.

When should the orders be reviewed?

58. The Board considered an administration order necessary for a period of three years with a review at the conclusion of the period or upon application by the parties.
59. With regard to guardianship, the Board considered that the limited functions of the Public Guardian could be discharged within a shorter period. Accordingly, the Board appoints the Public Guardian for 13 months with a review after 12 months of the operation of the order. It is the expectation of the Board that if appropriate

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regimes are found to be in place and working effectively at the time of the review, there should be no further requirement for an order.

Conclusion

For the reasons outlined above, the Board orders:

1. That The Public Trustee be appointed as the represented person's administrator.
2. That the powers and duties of the administrator be those conferred by Division 4 of Part 7 of the *Guardianship and Administration Act 1995*.
3. That the orders in paragraph 1 and 2, above, remain in effect to 9 October 2006.
4. That the Public Guardian be appointed limited guardian of the represented person.
5. That the powers and duties of the guardian be limited to ensuring that (i) policies, practices and competent staff are available to support the represented person's independent living and health care, and (ii) an appropriate schedule of medical treatment and review is established to monitor the represented person's well-being.
6. That the orders in paragraph 4 and 5, above, remain in effect to 9 November 2004.
7. That a review of this order be conducted within 12 months of the date of this order.

DATED this day of September 2003

Anita Smith

President