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**CRISIS IN GUARDIANSHIP:
COMMUNICATION AND COMPETENCE**

**SUBMISSION TO
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CRISIS IN GUARDIANSHIP: COMMUNICATION AND COMPETENCE

THE CASE OF ANNE McDONALD

Anne McDonald was born in 1961. She had severe athetoid cerebral palsy, could not walk or talk, and at the age of three was admitted to St. Nicholas Hospital, a state institution for people with severe or profound retardation, where she stayed for more than fourteen years.

In 1974 Rosemary Crossley came to St. Nicholas as a playleader. Over a period of years she developed a means of communication with McDonald based on supporting her arm and inhibiting her reflexes to enable her to point. She taught Anne McDonald to spell out words on an alphabet board¹. The Hospital did not accept the validity of this communication.

In 1979 Anne turned 18. After further disputes she expressed, through Crossley, a desire to leave St Nicholas Hospital and go and live with Crossley. The hospital was in a difficult legal position. Children who went into St Nicholas had not been certified in any way. No legal procedures had been required. If parents asked the hospital to look after their child, and the hospital agreed, then the hospital simply acted as if it had the same powers as the parents.

The Health Commission, the government agency which operated the Hospital, had never given any thought to the position of patients who had been admitted as children but had grown to adulthood.

The age of majority in Victoria is eighteen, and Anne had turned eighteen. Legally, her parents' rights over her had terminated and so, correspondingly, had those of the hospital. If Anne had been able to walk out of the hospital nobody would have had any legal grounds for preventing her departure. Despite this, the Commission proceeded on the assumption that some penumbra of guardianship remained with the parents and could be delegated to the Commission.

Anne could not walk out of St Nicholas, and St Nicholas had no intention of allowing anybody to walk out with Anne. The Commission's contention was that as McDonald only had the intelligence of a two-year-old she was incapable of forming an intention to leave, and therefore they were not keeping her against her will.

No formal avenue of appeal existed against the Commission's decision, and Anne McDonald was obliged to take an action for *habeas corpus* in the Victorian Supreme Court, which she won, the judge making an order that "It is ordered that the respondents not hinder the departure of the applicant from the premises known as St Nicholas Hospital, Carlton, in the company of Rosemary Crossley."

¹ Crossley R, McDonald A, *Annie's Coming Out*, Penguin Books, Melbourne, 1981

The outcome of the case contributed to a general pressure at that time for reform of the laws dealing with guardianship and with mental retardation.

THE NEW PARADIGM

St. Nicholas was closed in 1985 and its residents moved to Community Residential Units (CRUs). The law in this area was remade in 1986 with the introduction of the Intellectually Disabled Persons' Services Act 1986.

The Labor government of the time was sincerely committed to the principle of enforceable civil rights for people with intellectual disability, the principle of the least restrictive alternative, and the principle of integration into the community. Despite the good intentions of reformers, there were enormous gaps in their knowledge of disability and mental retardation. In the era when the legislation was drawn up the concept of mental retardation was regarded as comparatively unproblematic. Many of the issues that now concern people had not yet become evident; in particular,

- The discipline of Augmentative and Alternative Communication (AAC) was just coming into being. The Australian Group for Severe Communication (AGOSCI), for example, was established in 1981.
- The condition of autism was seen as a very rare condition rather than as either a complication or an alternative diagnosis in a significant proportion of diagnoses.

As a result, almost no writings on the requirements of a guardianship system felt it necessary to discuss the issue of how mental retardation should be assessed, or what legal protections should be attached to any such assessment. No consideration was given to the possibility that a person might be mentally capable but unable to communicate that capacity.

In general, the reforms attempted to combine the sometimes inconsistent principles that there were times when people with intellectual disabilities needed to be treated as vulnerable individuals in need of special protection and there were times when they needed to be treated as citizens in exactly the same way as everybody else.

The two imperatives – to prevent abuse without generating stigma – led to a decision that guardianship should be individualised, and, in particular, that it should be called upon only when necessary rather than being applied to all people in a particular situation. In practice, this meant that the Guardianship and Administration Act of 1986 Act could be brought into operation only by the joint operation of three criteria:

(1) If the Tribunal is satisfied that the person in respect of whom an application for an order appointing a guardian is made-

- is a person with a disability; and
- is unable by reason of the disability to make reasonable judgments in respect of all or any of the matters relating to her or his person or circumstances; and
- is in need of a guardian-

the Tribunal may make an order appointing a plenary guardian or a limited guardian in respect of that person.

Of the population of people with disabilities, only those who were both unable to make reasonable judgments and needed a guardian could have a guardian. This meant in practice that a judgment of inability to make a reasonable decision – a judgment of incapacity – would be made only in the case of those people where a dispute existed. The vast majority of people in state care would never be legally assessed for guardianship.

Practical considerations argued strongly in favour of this provision. For all people in state care to be assessed would require an enormous increase in the number of qualified professionals in this area (and, of course, the expertise required of such professionals has increased from a degree in psychology to a degree in speech pathology with a specialization in AAC) and would be an immense and difficult enterprise.²

However, the consequence of the double-barreled test is that it is impossible to conclude from the fact that someone is not under guardianship that they are legally presumed to be able to make reasonable judgments. It may be that they are regarded as being unable to make reasonable judgments but as having no need of a guardian.

The other effect of the absence of universal application of guardianship to all persons unable to make reasonable judgments is that the state has no legal relationship with the vast majority of persons in its care. The care of people with severe disabilities is treated as lying outside the sphere of positive law, relying on convenience, silence, and an unwillingness to push matters to their logical conclusion.

UNDISCLOSED ASSUMPTIONS

The state has a duty of care to the persons occupying its institutions and its residential units, but it has no power to have any dealings with them without their consent. If they are unable to give consent, direct or substituted, either because of mental incapacity or because of communication handicap, any action that carers take – feeding their charges, putting them into the bath, administering medicine, or putting them to bed – constitutes a criminal assault.

It is assumed, to bridge this legal gap, that people who are unable to live without care will be taken to have consented to that care, but that assumption has never been articulated, still less justified. As the people who are unable to give consent are also unable to make complaints, of course, this issue would come up only in the course of another dispute.

The problem with this practical arrangement is that when an issue does reach the stage of open conflict it is radically unclear what the legal situation is.

² Even if adequate legal protections were in place, they would of course by themselves be utterly insufficient to ensure that abuse of people with communication handicap was not occurring. Any care system that paid more than lip service to the importance of communication would require enormous investment in a chain of procedures beginning with the training of AAC therapists and ending in the training of all care staff in the use of communication devices. This expenditure is absolutely imperative.

RECENT CONFLICT

These issues have recently been brought into focus by a case with curious parallels to the disputes of thirty years ago.

Anne McDonald died suddenly in 2010. One of her last acts was to collaborate with a woman I shall refer to as Ms X, one of her surviving friends from St. Nicholas, on a conference presentation entitled ***What We Are Fighting for: Actualising the Right to Communicate***. Ms X, too, was a woman with severe cerebral palsy who could not walk or talk and used non-speech communication. The paper contrasted the situation of Anne, who lived in an environment that acknowledged, valued, and supported her communication, with that of Ms X, who lived in a DHS Community Residential Unit (CRU) that did none of these things.

The paper concluded with MS X's charge to the conference:

I'm used to being ignored. I have no say in my life. After passing many tests I still have no effective right to communicate. It's not my skills that are the problem – it's the unwillingness of staff to give the time and support necessary for me to use my equipment. Repeated attempts by advocates from [Communication Rights Australia] CRA to challenge this reluctance have been unsuccessful. Perhaps the UN Declaration will help.....

I ask all at the AGOSCI conference to take an active role in ensuring that nobody is gagged by neglect.

The paper was accepted for presentation both at the 2010 conference of the International Society for Augmentative and Alternative Communication (ISAAC) in Barcelona and at the 2011 conference of AGOSCI in Adelaide. Anne delivered the presentation in Barcelona, using Powerpoint and having the text read by Rosemary Crossley. After Anne's death, Ms X decided that she wished to deliver the presentation in Adelaide in memory of her friend. When X's parents were informed of this request, they forbade X to go to Adelaide.

The age of majority in Victoria is eighteen, and Ms X had turned eighteen in 1981. Legally, her parents' rights over her had terminated and so, correspondingly, had those of DHS. If MS X had been able to walk out of the CRU nobody would have had any legal grounds for preventing her departure. Despite this, the Department proceeded on the assumption that some penumbra of guardianship remained with the parents and could be delegated to the Department.

Ms X could not walk out of the CRU, and the Department had no intention of allowing anybody to walk out with her. The Department's contention was that as MS X only had the intelligence of a two-year-old she was incapable of forming an intention to leave, and therefore they were not keeping her against her will – or, rather that Ms X's parents did not believe that Ms X could communicate, and thus did not believe that MS X could say she wanted to leave the CRU, and thus did not believe that she had said she wished to leave the CRU; and because the Department accepted the parents' rights in this matter, it would not let Ms X go to Adelaide.

The parents also forbade Dr. Rosemary Crossley from visiting Ms X. The severing of a long-standing friendship that involved visits to Crossley's home overnight, outings to

plays and films, and trips to restaurants and festivals (all at Crossley's cost) might seem difficult to reconcile with a commitment to Ms X's best interests, whether or not one believed that she could communicate. Again, had X been under guardianship, this decision could have been appealed to VCAT; as she was not, it could not.

The problem is, in part, that the Department apparently held that it had made no judgment as to whether such visiting was or was not in Ms X's best interests (and Dr. Crossley continued to be allowed by the department to visit other clients freely, which would imply that the Department had no intrinsic objection to her character). The Department simply says that Ms X's parents did not wish Crossley to visit. Had the Department had any legal relationship with Ms X that decision would have been reviewable under that legislation; as it did not, it was not.

LEGAL VACUUM

Because the Department has no independent legal power over the residents of its institutions and CRUs (see below), it would seem that it is driven to fall back on the powers of the parents. The fact that the parents have no rights seems less important in this context than the fact that pretending they do relieves the Department of the need to take responsibility for decisions on the matter.

Nonetheless, for the carer of a person with a disability not under guardianship to feel that there was no responsibility on the carer and no power in the carer to take a decision in the best interests of a resident is an intrinsically unsatisfactory situation. And the displacement of decision-making on to family members who are not guardians obviously collapses if there are no family members in contact.

After continuing debate the Department encouraged Ms X's parents to regularize the situation by going to the Victorian Civil and Administrative Tribunal (VCAT) to seek guardianship over their daughter. While the outcome of the case is covered by the confidentiality provisions of the Act, no possible outcome does anything to remove the real and fundamental problems that underlie the situation of people in state care.

If, for example, VCAT were to have come to the decision that Ms X should not have a guardian, either because it found that she was capable of making reasonable judgments or because it found that she did not require a guardian, this would leave the legal situation unaltered, and it is not clear that the Department would have under those circumstances altered its stance that the parents were entitled to take decisions on Ms X's behalf. The guardianship legislation covers in some detail the legal burdens placed on a guardian to act in the best interests of the represented person, but no law at all covers the duties of a carer who is not a guardian, and no body reviews their conduct.

The only system of legal regulation of the duties and powers of a carer applies to a small minority of those caring for adults with a disability – those who are also guardians. This is a serious problem.

The purpose of guardianship legislation is to provide protection for persons in care. Inherent in this purpose is the assumption that carers will not always act in the best

interests of the person in care unless legal sanctions are in place, or at least available for use. At present, many adults in permanent care are left without the protection of any appropriate legal shield, as, indeed, are their carers.

Disability care providers have no legal right to deal in any way with those adults in their care who are not clearly able to give consent. This applies not only to their authority to detain them but also to their authority to provide physical care (feeding, changing, bathing). In the absence of any positive legislation, the law in theory regards any touching of the person by the carer without their consent as a criminal assault – a restriction so sweeping and absolute as to be ignored by all concerned.

Legislation exists (in Victoria, for example, the Mental Health Act 1986) for the compulsory commitment to care of persons with mental illness (the definition of which would seem to exclude both intellectual impairment and communication handicap). Such legislation provides legal authority for staff to administer such care, subject to any restrictions and patient protections provided by the Act.

The Disability Act 2006, like its predecessor the ID Act, contains no provisions for compulsory commitment of persons with a disability.

The Department would appear to interpret the absence of authority for its care of people with other disabilities not as a restriction on its powers but rather as the absence of any limitations on its powers.

Examples of this approach have been observed in the past. The Mental Health Act, for example, forbade the application of restraint and seclusion on involuntary patients except under strict conditions (and thus authorised their use under these conditions). St. Nicholas Hospital was not gazetted under the Act. The correct interpretation of the law would have been that it was therefore not authorised to apply restraint or seclusion at all: the Hospital's interpretation, however, was that it could apply restraint without the limitations that restricted gazetted institutions.

COMMUNICATION IMPAIRMENT

The problem is exacerbated by the overlying problems of communication impairment. The Guardianship and Administration Act, despite its origin around the time of the Anne McDonald case, does not contemplate the situation of a person who has the capacity to make reasonable judgments but who suffers from an impairment in their communication such that they have difficulty expressing these judgments. Indeed, the Department (and society at large) tends to operate on the basis that a person who cannot communicate can be presumed to be intellectually impaired.

People who can make reasonable judgments but have difficulty expressing them clearly exist. We might imagine as our type case Anne McDonald (or, alternatively, English astrophysicist Stephen Hawking without his powered wheelchair and his communication devices). Such people may well require special legal protection, in the form of having some form of legally authorized advocacy provided to ensure that major decisions were taken in line with their wishes; however, this is impossible under the present law, under which the ability to request guardianship is a disqualification from receiving it.

Without the external power of a guardian in prospect, a carer is, in practical terms, free effectively to imprison the person with communication difficulties and disregard their wishes. No specific legal penalties attach to this, and no means of specific legal review is provided.

Many people who are regarded as intellectually disabled to the point where they are unable to make reasonable judgments have never been given a formal intellectual assessment. Most have never been given a communication assessment by a person with expertise in AAC³. Virtually no care staff have any training in the use of AAC devices with people with disabilities.

When the issue of communication is raised in guardianship hearings it arises only as a preliminary enquiry in the course of determining whether or not a person is capable of making reasonable judgments. The carer, of course, has custody of the person concerned, and there is no legal responsibility on the carer to permit any independent assessment of the person's communication.

It has been suggested, however, that in the absence of communication it is intrinsically impossible for the Tribunal to be satisfied, as the law requires, that a person is unable to make reasonable judgments, on the grounds that a person unable to make reasonable judgments and a person unable to communicate reasonable judgments would have present identically. This point has not yet been argued before the Tribunal, but might well arise on appeal.

The assessment of communication is not a mechanical operation, and two therapists can easily come to different conclusions. It is at this point that the issues of onus of proof and degree of certainty arise – and retreat unsatisfied, as no legal answer is given to either question. It is not clear whether the onus is on the carer to demonstrate that the carer cannot communicate, or whether (as carers tend to assume) it is for any party asserting that the person can communicate to demonstrate that communication. The issue of what standard of proof is appropriate in either of these cases is utterly untried.

There can be few situations more utterly horrific, more soul-destroying, and more dehumanising than to have the capacity to communicate but to be denied any opportunity to express this capacity. It would surely be worth almost any effort to prevent such a horror. It is impossible to be certain that under existing law and existing therapy provision such cases do not arise.

For a person who could communicate to be treated as if they could not communicate – to be given no training in communication, to be given no equipment with which to communicate, to be given no education to make use of their communication – is to destroy their life and smother their self. There can be no decision more important. As Anne McDonald said, nobody without communication

³ One group of therapists has attempted to remedy this lack by producing an assessment instrument (the Triple C) that can be administered by untrained care staff. This test, while founded on no adequate evidence, has the advantage, from the point of view of a parsimonious government, that no possible combination of answers can indicate that the person being tested either (a) is literate and requires communication support or (b) is capable of literacy and requires the attention of a trained therapist.

should be assumed to be incompetent on any lesser evidence than it would take to imprison them for life.

RECOMMENDATIONS

1. Guardianship legislation should provide for the situation of people who are capable of making reasonable judgments but unable to communicate those judgments.
2. Legislation should be introduced to govern the situation of persons under state care who are viewed as unable to give consent to care, such legislation providing judicial review of decisions as to care taken by the State.
3. Where persons are regarded by the State as unable to give consent to care, such determination should also be subject to judicial review.

Chris Borthwick

Appendix I

Documentation

The case of X, referred to above, demonstrated that the Department of Human Services made no distinction between parents who had been awarded guardianship of their children and parents who had not:

From: Cathie Cerolini

To: Rosemary Crossley

Date: Tue, 3 May 2011 12:25:17 +1000

Subject: **Re: Review of Support Plan for [X]**

Rosemary

There is no VCAT appointed Guardian for [X]. The family is recognized as acting as [X]'s Guardian.

Cathie

Cathie Cerolini | Disability Accommodation Services | Manager
- Inner |