

'IN CARE'

— KILL OR CURE

Rosemary Crossley

INTRODUCTION

Most readers will be aware of Rosemary Crossley's work with Anne McDonald and the court case which gave Anne permission to leave the institution and live with Rosemary. The following article reflects Rosemary's strong concern with respect to the care of residents of institutions. We publish the paper because it reflects the personal view of someone who has been involved in the care of children with disability.

Ms Crossley's book 'Annie's Coming Out' is reviewed in this issue. Page 26. — Editor.

This paper is a very personal look at how the State of Victoria has fulfilled its parental responsibilities towards the disabled people who live in residential institutions.

Institutions may cause harm without ever performing an overtly harmful act. Sins of omission may cause more damage than sins of commission. Children are especially vulnerable if care is omitted, the most extreme example being the baby who relies on others to fulfill its most basic needs. Some severely disabled people require this level of care permanently. Any child will be disadvantaged if uneducated, however the disabled child may suffer even more than the normal child, who will at least learn to walk and talk without special training. Without special aids, education and therapy the disabled child, who may have sensory or physical problems apart from or in addition to any intellectual disability, may not be able to start learning at all. Without intervention his disabilities may worsen — the temporary hearing loss becomes permanent; spasticity produces musculo-skeletal deformities. Not only

does the child not improve, he acquires new handicaps.

In Victoria, there is *no* State accommodation for disabled children outside mental retardation institutions. Disabled children in State care usually live in large Health Commission institutions covered by the 1939 Mental Health Act, which is primarily concerned with the needs of adults with psychiatric problems. (The Act is being reviewed as this is written.) In addition, some hundreds of children live in "informal" State-run institutions not covered by the Act and an even smaller number come under the umbrella of the Department of Community Welfare Services, which is responsible for normal children in care. The latter are generally "boarded out" to charitable organisations such as the Spastics Society. Community Welfare Services has also recently established a small but effective adoptions scheme for its disabled wards of State.

Disabled children not in State care either live at home (the vast majority) or in the limited accommodation provided by private charities concerned with specific disabilities. The more seriously disabled a child is the more likely it is to end up in State care. For example, a high proportion of children who are both deaf and blind live in institutions for intellectually disabled children, which are without services they so desperately require.

There is nothing in the Mental Health Act that establishes who is the retardation service's client — the parents or the child. Relationships and responsibilities between parent and child, service and child, and service and parent are not spelt out. Neither is any relationship with "normal child" services mentioned.

In fact the dichotomy between "normal child" care in Victoria and "disabled child" care makes me wonder whether the State has ever considered the disabled young as children.

When children first come to notice as requiring care, they are automatically drafted to the "appropriate" service — normal to Community Welfare Services, apparently retarded or severely disabled to Mental Retardation Services. This sorting may be done at birth. It is almost irrevocable — there is very little movement between the two systems.

As well as a different orientation towards child care (which it does not see as a medical problem), Community Welfare Services has a clear view of who its clients are. Section 41 of the 1980 Act states:

"the welfare of the child or young person shall be the first and paramount consideration and any provision made for physical, intellectual and spiritual development shall be such as a good parent would make for his child".

This applies to all children in the care of the Department. I am informed that in practice this means that the needs of the child are paramount and that while parental wishes may be taken into account they will be over-ruled if considered not in the best interests of the child.

Another Act of great significance for Community Welfare Services is the Adoption of Children Act 1964. Under Section 29 the Court may dispense with the consent of the child's parents or guardian to the *adoption* of the child where the Court is satisfied:

"that the person has, for a period of not less than one year, failed, without reasonable cause, to discharge the obligations of a parent or guardian,

as the case may be, of the child".

In practice, in the case of a child in care, failure to visit for a year could be sufficient ground for consent to be dispensed with. In theory this Act applies to disabled children equally with normal children. During the year 1978-79 parental consent to adoption was dispensed with for 12 normal children; 51 children were the subject of applications for dispensation in the course of preparation.

To my knowledge, the clear intent of these Acts, that the child's needs are supremely important, has never been held to apply to children in Mental Retardation Institutions. Neither has the provision that care shall be such as a good parent would provide.

What is the result of this dichotomy in real terms, that is in the lives of the children in care? How has the State fulfilled its parental responsibilities to its disabled children?

Anne McDonald was admitted to a State institution for severely and profoundly retarded infants aged nearly four. She weighed 10 kilos. She was assessed as a severely retarded spastic quadriplegic. She was provided with no education whatsoever for the next 10 years. She had physiotherapy for three months out of the 14 years she lived in the institution. She had no speech therapy. She was given no wheelchair, no boots, and had no private clothes or belongings. She almost never left the ward in which she lived with 40 other children and in which she spent her days lying on the floor, unable even to see out of the window. When she was 16 Anne visited my house for the first time. She weighed 13 kilos — a gain of three kilos in 12 years. She had grown about 10 cms in the same period to be 105 cm tall.

In 1979, after 14 years in St. Nicholas, Anne was given her first psychological assessment since admission. Now 18 and found to be of "at least" average intelligence, she took her case to the Supreme Court and won the right to leave St. Nicholas. She now lives with me. Currently she weighs about 32 kilos and is about 128 cm. tall. With speech and physiotherapy, plus appropriate equipment, she is beginning to achieve a little intelligible speech and the ability to walk with support. How useful these skills will be remains to be seen, but the fact that she is able to develop them at all at age 20 is a clear indication that she had the potential to do so earlier, had she been given the opportunity. One can only wonder at what she may have lost by not starting therapy till age 18. This year Anne is studying H.S.C. English

Expression at University High School evening classes. Her results to date have been quite acceptable.

Anne's development since leaving St. Nicholas says something about Anne but a lot more about the institution. It is not individual staff who were at fault. It is the State, which has a tradition of neglect towards its disabled children, neglect so horrifying that if it occurred in a private home the Children's Protection Society would be expected to act on it. Neither is it important that Anne is intelligent. This would be indefensible even if she were profoundly retarded.

The obvious question is — has the situation improved since Anne left St. Nicholas in 1979? I will talk about St. Nicholas specifically, even though I was removed from the hospital in 1980 and my information is necessarily second-hand. My impressions are:—

- many of the residents still receive little or no education, physiotherapy and many have not wheelchairs and boots;
- no speech therapy is provided;
- few residents have had a psychological assessment;
- four occupational therapists joined the staff in June this year.

"Spiritual" care is also mentioned in the Community Welfare Services Act. Interpretations of this differ — I would suggest that in context it was intended to encompass all aspects of child rearing not directed to physical or intellectual development, in particular the provision of the social and emotional experiences necessary for personality development. What provision does the State make for the emotional needs of the disabled children in its care?

Disabled children have no security in caretakers, guardians or friends. Every attempt is made to discourage attachment to staff, both because it is "unprofessional" for staff to be involved with "patients" and because staff are at the mercy of the rosters which ensure that the maximum number of staff handle the children for the minimum period of time. In St. Nicholas each resident is likely to be fed and dressed by fifty people each year.

One would normally expect parents to be the guardians of their children. If the parents are not around or not interested, one would expect other provisions — wardship, guardianship, adoption — to be made. This is the case with normal children — steps are taken as a matter of course to provide alternative protectors for the child lacking active parental involvement.

The situation of the disabled child is completely different — there are

children in St. Nicholas who have not seen their parents since they were admitted to the hospital many years ago. Nonetheless the Health Commission assumes all these children are the property of their parents and that any life or death decision should be made by their parents. In my six years at St. Nicholas the administration made no attempt to contact parents unless such a decision was called for. Sometimes the only 'contact' the parents of a child had, in all its years in the institution, was when they were asked to arrange for an undertaker.

Ironically, having never encouraged parental involvement, the Health Commission feels that the residents in its institutions should remain under parental control for life. Many St. Nicholas residents have now turned 18, and have the same rights as other adults — ourselves, in fact. When the Minister of Health was asked about this, his response was, "The fact is we are not talking about normal children or adults but of people who are unable to function in the normal way" and hence, in his view not entitled to be treated like other people.

Rights and emotional security are bound together. St. Nicholas Hospital has banned "non-relative visitors", that is, visitors who are not family members, to a number of its residents. The Minister says:

"The position is that parents who have given consent to their children being visited by other than direct family members can receive these visitors. Others may not. I see no reason for interfering with that very sensible direction."

This seems reasonable until you realise that there is no burden of responsibility on the hospital to advise parents that their consent for visitors is required. Any resident whose parents are not in contact can automatically have all visitors banned. This is regardless of the fact that the friendship between resident and visitor may pre-date many years the introduction of this regulation in late 1980. As well, no responsibility attaches to parents who ban visitors. They are not obligated to visit themselves, or to give any reasons why they wish visitors banned. This direction is, in fact, a licence for the institutions to isolate their residents completely from the community, and a licence for the community to lock up their children.

- Anne McDonald, who is not allowed

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to visit any of the people she lived with for 14 years because "none of the parents have given permission".

- Stephen, aged 18, who has not seen his parents since he was admitted to St. Nicholas, aged five. All Stephen's friends have been banned from visiting, including children as young as seven.

- Phillip, aged 16, whose mother came to visit him last year for the first time that anyone could remember since his admission at the age of one. She had to ask a nurse to show her which one he was, and to introduce her. She stayed 10 minutes. There has been no parental contact since then. All Phillip's friends have been banned from visiting.

- Noelene, aged 15, who hasn't seen her father, a single parent, since her admission seven years ago. The last contact he had with the hospital was some four years ago when he saw a social worker and wrote a note of permission for a volunteer who was interested in Noelene, giving her leave to take Noelene to her home for outings. In late 1980 the hospital declared that this permission was no longer valid, despite the fact that they had not been in touch with her father, who is an itinerant worker. The volunteer has tried to visit Noelene several times since and has been refused admission, as have all Noelene's other friends.

The parents are not to blame for the situation of their children. The State has encouraged them to believe that their children are receiving the best of care and has effectively discouraged them from retaining involvement.

Possibilities for change exist. Victoria has a new Mental Retardation Division with many enthusiastic and forward-looking staff. The Mental Health Act and guardianship provisions are under review. Providing that the new initiatives are not stifled by the politicians or the budget, there is hope that the State will start to care for *all* its children.

Coda

The base-line requirement for a welfare service must be that it does no harm. There is an especial duty not to harm if the client has not sought the service, and has no way of withdrawing from it.

A service shown to harm its clients has three alternatives:

- It can reform itself. Reform has to be immediate or option three comes into effect by default.
- It can cease operations on the ground that reform is impossible.
- It can redefine itself as a penal service.

FAMILIES, CHILDREN AND ALCOHOLISM

Abstract: In dealing with alcohol abuse, a focus on the family is of importance. Conversely, in dealing with problematic children or families there is good reason to recognise the possibility of alcohol abuse. Awareness of the possible adaptiveness of alcohol in the family may assist the professional in helping the family to move.

INTRODUCTION

Practitioners in the field of alcohol and drug dependence are constantly aware of the profound effects of their clients' abusive drinking behaviour. Figures demonstrating the devastation to livers, brains, the road toll, driving licences and job performance abound. Although there has been increased awareness of family issues, this dimension is still low in the priority ratings of most alcoholism practitioners. Undoubtedly funding is attracted more readily for the prospect of reducing the road toll, treating defined medical problems, or reducing the high levels of problems in the workforce which are directly attributable to alcohol. Alcohol and drug agencies tend to operate within a medical orientation and/or a variety of intrapsychic psychological orientations. Interpersonal dimensions relating particularly to the family, tend to be ignored in favour of dealing with the individual and his or her psychopathology which expresses itself in substance abuse. Certainly in my working experience in three of Melbourne's agencies, I have become acutely aware of the powerful culture that assumes that once the individual has begun coping with their own problems, the family will spontaneously resolve its dysfunctional status. The attitude is changing but history still preserves the culture.

Current Work

The body of knowledge developing

from the practice and research of a number of family workers makes it increasingly apparent that families are generally inextricably involved in the maintenance as well as the potential cessation of problematic alcohol use. The satisfaction I have experienced in seeing very visible movement in families together with their alcoholic members, personally confirms the importance of dealing with a whole system and has led me to work almost exclusively on the family level. I have been moved to start thinking "systems thinking", gain skills in family therapy, and encourage fellow workers and myself to overcome the fears of looking beyond the individual.

By the same token, it is striking how cautious many helping professionals are in identifying and tackling substance abuse. Steinglass believes that when alcohol abuse is evident, the behavioural and physical consequences are so overwhelming that it is hard to envisage a successful outcome to treatment and the case is unlikely to progress beyond the assessment stage. Professional stereotypes of alcoholics are also dissuasive, with images of poor motivation, self-indulgence and self-destructiveness. In fact only a small proportion of alcohol abusers can be categorized as such, and an even smaller number fit the "skid row" image. People with alcohol problems come in all shapes and sizes, and can be equally problematic being abstainers*, social drinkers, heavy drinkers or addicted drinkers. This too presents a problem of definition as to whose drinking is dysfunctional and whose is not.

Images of drunkenness can be distasteful to the professional if in fact they are real. Some workers have claimed to be deterred by threats of violence. However, real danger appears no greater than in any other area of health and welfare. According to