The effects on siblings of the institutionalization of the retarded child in the family.

C. Pamela Ayland
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UNIVERSITY OF WINDSOR
The School of Social Work

THE EFFECTS ON SIBLINGS OF THE
INSTITUTIONALIZATION OF THE
RETARDED CHILD IN THE FAMILY

by
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Gordon Markham

A research project presented to the School of Social Work of the University of Windsor in partial fulfillment of the requirements for the degree of Master of Social Work.

September, 1973
Windsor, ONTARIO, CANADA
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ABSTRACT

This exploratory research study was undertaken to determine what effect, if any, the institutionalization of a retarded child has on the siblings of that child. The sample for the study was drawn from siblings of retarded children presently residing at the Ontario Hospital School, Cedar Springs, whose families were living in the County of Essex at the time of the study. The information was obtained by means of a questionnaire mailed to the siblings.

The responses of the siblings indicated that their personal adjustments were affected as a result of the institutionalization process. The siblings did not appear to be involved in the planning or implementation stages of the institutionalization. The siblings did appear to be accepting of the institutionalization as the best thing for the retarded child.

The findings indicate that there is a need for more direct contact with siblings to investigate their feelings and concerns at the time of institutionalization and to offer counselling services to assist them in their acceptance of the institutionalization.
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CHAPTER 1

INTRODUCTION

Background

This research project developed from observations that were made during our respective work experiences at a child welfare agency and at an institution for retarded children. When a retarded child is to be placed in an institution, the standard procedure at an Ontario Hospital School is to provide the parents and the child himself with social work services. An attempt is made to help these family members prepare for the child's move from the home, and to help them to understand the implications and effects such a placement will have on them individually as well as collectively. Through our experiences and examination we came to realize that in these situations very little effort is put forth to include the siblings of the retardee in the planning, implementation, and follow-up stages of the institutionalization. We felt that if these siblings were not given the opportunity to express their feelings about the retardee's placement in an institution, and if they were denied the right to
participate as a family member in the admission procedures, their attitude towards the retardate's absence from the home could be affected. This exclusion of the siblings of the retarded child from the professional services provided for the other members of the family could result in adjustment difficulties for these siblings after the institutionalization has taken place.

Purpose of the research

Our intent for this exploratory research project was to determine to what extent the siblings of retarded children are affected by the institutionalization of their retarded brother or sister. Stated more specifically, we were interested in ascertaining whether there was evidence that would indicate the siblings could benefit from direct social work services at the time a retarded child is admitted to an institution.

On the theoretical side, indications resulting from this research project that siblings do experience adverse reactions attributable to the institutionalization of the retarded child could provide useful material for further experimental research in this area. More practically, if the assumed negative effects do have
some basis in fact, this could encourage professionals to plan their intervention with such families so that the siblings of the retarded child are included.

One of the assumptions we made prior to carrying out this research project is that the removal of a retarded child from the family unit upsets the homeostatic balance of that family.

Family theory

The literature on family theory indicates that the removal of any member of the family has an upsetting effect on the family's homeostatic balance.

The trend in modern literature is to view the family as a system. Scherz states that the family is a system composed of two or more units interrelating in such a way that a change in one unit influences behaviour in the other and the reaction of the second unit in turn affects the first.¹ As a system, the family consists of interacting dyads and triads which relate to one another according to set family rules.²


In order for the family system to function there must be a complimentarity of roles so that a level of homeostasis can be maintained. Scherz points out that family roles are assigned and accepted according to the needs of the individual as well as the needs of the family. Both Strean and Speigal maintain that no family roles exist in isolation and many reciprocal roles are carried out automatically within the family to maintain balance.

Jackson's concept of family homeostasis implies that there is a "relative inconsistency of the internal environment, a constancy, however, which is maintained by a continuous interplay of dynamic forces". Ackerman feels that homeostasis signifies the capacity to adapt to change and to withstand pressures both as individuals

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and as a family. Thus, he states "homeostasis can be understood only within the continuum of individual, family and society".7

Goodwin and Mudd say that "disequilibrium occurs when ... complimentarity of roles is disturbed, and the expectations of each from the other are disappointed with the resultant tension, anxiety and frustration occurring".8 When the family balance is threatened, there is an attempt to re-establish equilibrium and maintain the family balance.9

... the family maintains an equilibrium within itself and toward the environment which is comparable with homeostasis, the mechanism by which the individual organism maintains itself in a state of balance. The members of the family may be compared to the organs of the body, in spite of obvious differences. Although the intra-family relationships are not often essential to life, each individual is profoundly affected by the others, and by the family as a whole ... The welfare of the family depends not only on the characteristics of the individual, but also on the capacity of the family to maintain a stable equilibrium internally and with reference to the environment.10


8Hilda M. Goodwin and Emily H. Mudd, "Indications for Marriage Counseling: Methods and Goals," Comprehensive Psychiatry, VII (October, 1966), 453.


The roles adopted by family members in an attempt to establish family homeostasis will have to be readjusted in order to achieve a new family homeostasis if a family member is removed from the family constellation. As stated by Ross, "the removal of any family member from that system will have an effect not only on the other individuals but also on their interaction and role balance".  

If the homeostatic balance within a family after the separation of one of its members cannot be re-established spontaneously, the need for intervention of a family therapy nature may be indicated. Likewise, the institutionalization of a retarded child may further emphasize the need for family therapy. Since the siblings are an integral part of the family system, the loss felt by them during such a separation could be dealt with not only indirectly through services provided for their parents, but also, perhaps more effectively, through direct service.

Sibling relationships

The sibling relationship is viewed as one of the subsystems within the family unit. The other subsystems are the parent-parent and the parent-child relationships. Since the subsystems are inter-related, a deterioration in one is likely to result in a deterioration in the other.12

Framo states that the sibling relationship is a very powerful subsystem. It provides a testing ground for children to express both negative and positive feelings which they might find difficult to express directly to parents, and the siblings can provide protection and support for each other against the parents and against threats from outside the family.13

A strain can occur in the sibling relationship when one or both parents favour, overprotect, or scapegoat one particular child in the family.14 It is these different roles that children fulfill in the family which contributes to the diversified personalities of the children.15

12Stran, The Casework Digest, p. 70.


The list of possible roles a child could fill in the family is endless. Each family will have a combination of roles filled by each member which allows it to maintain its own unique equilibrium.

The sibling subgroup as a part of the family unit can, of itself, affect the homeostatic balance of the family. As such, it would seem that an upset in this sibling subsystem has repercussions on all the members of the family. Similarly, the strain on the normal brothers and sisters caused by the institutionalization of a retarded child affects not only the brothers and sisters but also the parents and the relationship that exists between these two subgroups of the family.

"The sibling relationship itself must be examined in all its complexity 'within the context of the family gestalt'." 16 It is because of this factor that counsellors have turned towards the use of family therapy and diagnosis to understand and examine sibling relationships.

Review of the literature

There are very few studies available pertaining directly to our research topic of sibling reaction to the institutionalization of a retarded brother or sister. In fact, as pointed out by Einstein and Moss, there has been generally a lack of research dealing with the sibling relationship. 17

Fowl states that in the field of retardation "little notice...has been given to those who have a personal relationship to the retarded individual, namely, the parents and siblings of the retardate". 18

In 1960, Caldwell and Guze stated that one can find almost no literature relating to the effects of institutionalization for the retarded child upon other members of the family. 19 Ten years later, Hersh echoed...

17 Ibid
their statements: "Separation of a retarded child from his family by institutionalization, long a culturally supported phenomenon, has been the subject of much interest but of little systematic investigation."20 Even less information is available on such a separation as it relates specifically to the sibling of the retarded child.

What little literature is available on siblings of the retarded has certain limitations. Robinson and Robinson indicate that "by far the majority of those (i.e. studies) available . . . have been entirely subjective or much too small to be very helpful: most have failed to compare the siblings of handicapped children with children in unaffected families."21

Our review of the literature will be divided into two main sections, each containing two subsections. The first part will deal with reactions to retardation, firstly the reactions of the family and, secondly, the reactions of the siblings. The second major section in our review of the literature will discuss reactions to institutionalization, also divided into reactions of the family and reactions of the siblings.


Some of the limitations of the major studies to be cited will be outlined here. This should eliminate the need to repeat these limitations each time a reference is made to a study.

Bernard Farber has done the most widely recognized research in the areas of retardation and institutionalization of the retarded child and their effects on family integration. His numerous reports based on this research illustrate four main limitations to the study. Firstly, the families used in Farber's sample were overly concentrated in the middle classes so were not always representative of his population. Secondly, some of his comparisons were sometimes based on small, unequal numbers of his sample. Farber used no control groups in his study and, finally, the behavior of the siblings was inferred primarily from the reports of the mothers.

In the study by Caldwell and Guze, we see that the matching processes they used were so questionable that


23 Caldwell and Guze, "Adjustment of Parents and Siblings".
the interpretations that can be drawn from the research are seriously limited. Also, they as well as Grossman\textsuperscript{24} used very small samples in their studies.

The common criticism that can be made of the works by Tizard and Grad\textsuperscript{25} and Holt\textsuperscript{26} is that neither study made use of a control group.

Both Strauss\textsuperscript{27} and Rosen\textsuperscript{28} did studies on the reactions of siblings to their retarded brother or sister, but both relied on information from the mothers upon which they based their conclusions of the siblings' adjustment. This same criticism can be made of Barsch\textsuperscript{29} in addition to the fact that he spoke to only the mothers

\textsuperscript{24}Frances Kaplan Grossman, "Brothers and Sisters of Retarded Children," Psychological Today Magazine, April, 1972.


\textsuperscript{26}K. S. Holt, "Home Care of Severely Retarded Children," Pediatrics, XII (September, 1958).

\textsuperscript{27}M. A. Strauss, "Interaction with Retarded Siblings and Life Goals of Children," Marriage and Family Living, XXV (February, 1963).


\textsuperscript{29}Ray H. Barsch, "Explanations Offered by Parents and Siblings of Brain-Damaged Children," Exceptional Children, XXVII (January, 1961).
yet repeatedly refers to the information he received from the "parents".

In summary, the recent trend in viewing the family as a system is leading researchers to investigate all members of the system as they influence each other and the family as a unit. Research is beginning to be directed towards the sibling subsystem in the family and, in particular, the question of the effects of the retarded child on his siblings. Such research is being conducted in more depth without making the parents the major focus for study.

As stated by Dr. Goldberg, Director of the Children's Psychiatric Research Institute in London, Ontario:

For years, the professionals have placed the responsibility for the attitudes of the normal brothers and sisters on the attitude of parents. In the next ten years, I predict there will be an increasing emphasis on the study of these reactions and on more specific ways of meeting the needs of the normal child in such a family.

CHAPTER II

REVIEW OF THE LITERATURE

Reactions to retardation

Family reactions.--

The impact of a retarded child on the parents and siblings cannot avoid being traumatic to one degree or another. The family itself is immediately differentiated by virtue of having a 'special', 'different', or 'exceptional' child. The family roles, structurally and dynamically are affected by the interactional relationship with the retarded member.31

It is generally acknowledged that the presence of a retarded child within the family unit does have an effect on the family members.

There is some controversy whether having the retarded child in the home is always a disruptive factor on the family integration. Grossman32 says that the presence of a retarded child may enhance, or at least not hinder, the family functioning in some cases. She states that it is the family's definition of the problem that can


lead to the difficulty. Holt\textsuperscript{33} found that the effects on the family can be a gain of better spiritual and ethical values. Caldwell and Guze\textsuperscript{34} found that keeping the retarded child at home did not have an adverse effect particularly when the family received professional assistance from social workers and psychologists.

The recent trend in viewing the family as a unit can be applied to those families with a retarded child. Farber\textsuperscript{35} says that the presence of a handicapped child within the family creates imbalances and necessitates changes in role functioning. He speaks of the family passing through different stages in their life cycle. These stages are designated as: the married couple; the family with the youngest child of preschool age; the family with the youngest child a preadolescent; the family with the youngest child an adolescent; the family with all adult children; and the family with all married children. Farber states that the presence of a retarded child in the family arrests this family cycle no matter where the child occurs in the sibline, because the retardate becomes the 'youngest' and the family never progresses.

\textsuperscript{33}Holt, "Home Care," p. 754.

\textsuperscript{34}Caldwell and Guze, "Adjustment of Parents and Siblings," p. 858.

\textsuperscript{35}Farber, "Effects on Family Integration," pp. 6-7.
beyond the stage of having a 'preadolescent youngest child'. This changes the life goals of the parents in that they can never look forward to a time when all of their children will be independent, having reached the stage of adulthood. Ross\textsuperscript{36} supports this view in that he sees the retarded child as being dependent for a longer period of time and therefore requiring a more intense involvement by parents in a caretaking role.

Birenbaum concludes from his search of the literature in the area, that a retarded child within the family creates problems, sometimes of an almost unmanageable nature, thus straining the family's resources.\textsuperscript{37} Kessler agrees that a retarded child affects the family in a negative manner whether the child is or is not maintained in the home.\textsuperscript{38} Stephen Fleck states that "inborn defects in a child, whether inherited or not, have serious implications for the entire family and may distort structure and dynamics to a pathological degree."\textsuperscript{39} Koch and Dobson state

\textsuperscript{36}Ross, Exceptional Child, p. 119.


that their evidence indicates that a family with a 
retarded child have more problems of child-rearing, 
marital adjustment, and sibling relationships. 40
Farber talks about the quality of the relationship 
between the parents and the retarded child, or the 
siblings and the retarded child per se, as a major 
factor affecting the family stability. 41

In Australia, Schonell and Watts 42 found that 
the problem is not so much one of the individual sub-
normal child's care disrupting the family, but the 
pressures placed on the whole family by society of an 
economic, social and emotional kind. Koch and Dobson also 
agree with this point. 43 Grossman as well illustrated in 
her study that "sociocultural status has far-reaching 
consequences on the families of retarded children". 44
Without sufficient support and available resources in the 
community, families in the lower socioeconomic bracket 
suffered greater strain on their reserves and were called 
upon to provide care for the retardate without assistance

40 Koch and Dobson, Retarded Child, p. 270.
41 Farber, "Maintenance of Integration," p. 90.
42 Fred J. Schonell and B. H. Watts, "A First 
Survey of the Effects of a Subnormal Child on the Family 
Unit," American Journal of Mental Deficiency, LXI (July, 
1956), 718.
43 Koch and Dobson, Retarded Child, p. 269.
from outside sources. Kaplan and Fox⁴⁵ point out that not only are the families expected and required to care for the retarded child but they are often harassed or ostracized by the rest of the community.

Some authors agree that the presence of a retarded child in the family can enhance that family's functioning and it has been pointed out that the family suffers no adverse effect particularly if there is available social work or psychological intervention.

On the other hand, a majority of authors claim the retardate does have an adverse effect on the family such as imbalances which necessitate changes in role functioning, and the creation of dependency on the parents for a longer period of time. These authors agree that the retardate creates problems and affects the family in a negative manner no matter what the other circumstances of the family may be. It has been stressed that beyond the problems of caring for the retarded child are problems of an economic, social and emotional kind as a result of having a retarded child.

All of the research done in the area of the effects a retarded child has on the family unit agrees with our earlier statement that there is some effect on the family. The opinions are divided, however, when it comes to the question of this effect being positive or negative. The majority of the studies seem to indicate that in either case, these families with a retarded child experience stress, sorrow, and confusion that warrants the consideration of all society, not only professionals, to assist them with this potentially disrupting factor in their lives.

Sibling reactions. -- As stated by Koch and Dobson, having a retarded sibling causes problems for the normal children - a fact which is beginning to take on more emphasis and receive more attention. Kaplan and Fox say there is always some effect, in general, of growing up with a retarded sibling and often this may be a source of continuing psychological difficulty. Barsch points out that normal children will


\[47\] Kaplan and Fox, "Siblings of the Retarded," 500.

imitate the views of the parents on retardation. Several authors agree with this point and say that siblings of retarded children as a group will not have any problems particular to the retarded child as long as the parents have adjusted to this fact. Wolfensberger\textsuperscript{49} states that siblings are no better nor worse adjusted than comparable children in general and they will reflect the parental views. Caldwell and Guze\textsuperscript{50} found that the siblings mirrored the maternal values and were as well adjusted as the parents, so they concluded that the retarded child had no detrimental effects on the siblings. Rosen\textsuperscript{51}, and Robinson and Robinson\textsuperscript{52} also concur with these opinions. Koch and Dobson\textsuperscript{53} found that


\textsuperscript{50} Caldwell and Guze, "Adjustment of Parents and Siblings," 860.

\textsuperscript{51} Rosen, "Mother's Understanding," 526.

\textsuperscript{52} Robinson and Robinson, "Retarded Child," 523.

\textsuperscript{53} Koch and Dobson, Retarded Child, p. 270.
the attitudes and reactions of the siblings will follow those of their parents.

Gralicker, Fishler, and Koch\textsuperscript{54} state that the presence of a young retarded child in the family does not adversely affect the teenagers especially when counselling is available to help maintain the family. In fact, Blodgett\textsuperscript{55} found that many teenagers felt they had developed strength, understanding, tolerance, patience and fortitude they may not have had otherwise. She states that the general picture from her point of view is one of a well-adjusted but not particularly contented group.\textsuperscript{56} Birenbaum\textsuperscript{57} states that difficulties between retardates and their siblings resemble the classic sibling rivalry that would be seen between normal children.

On the other hand, there is evidence that having a retarded sibling does create problems for normal children.

\textsuperscript{54}Betty Gralicker, Karol Fishler, and Richard Koch, "Teenage Reaction to a Mentally Retarded Sibling," \textit{American Journal of Mental Deficiency}, LXVI (May, 1962), 843


\textsuperscript{56}Ibid., p. 168.

\textsuperscript{57}Birenbaum, "Mentally Retarded Child," 61.
that does require special understanding.\textsuperscript{58} Adams would regard the problems of the siblings of the retarded as a normal response to a highly stressful situation.\textsuperscript{59} Holt found that twelve per cent of the families in his study reported significant emotional disturbance among the normal children.\textsuperscript{60} Although his lack of the use of a control group presents difficulties in interpreting this figure as either high or low, it does provide some indication that problems exist.

Farber states that it is not the mere presence of a retarded sibling but the amount of responsibility assumed by the normal siblings for the care of the retardate which is the adverive factor.\textsuperscript{61} Strauss found that sustained interaction with the retarded sibling came to be regarded as a duty and resulted in the internalization of life goals that called for dedication and sacrifice.\textsuperscript{62} Although Robinson and Robinson felt that

\begin{itemize}
\item \textsuperscript{59}Margaret E. Adams, "Siblings of the Retarded: Their Problems and Treatment," \textit{Child Welfare}, XLVI (June, 1967), 311.
\item \textsuperscript{60}Holt, "Home Care," 752.
\item \textsuperscript{61}Farber, "Maintenance of Integration," p. 78.
\item \textsuperscript{62}Strauss, "Life Goals," 96.
\end{itemize}
siblings of the retarded were no better or worse adjusted than others, they did feel there could be serious problems if the siblings were pushed aside or were expected to assume maturity and responsibility beyond their years.⁶³

Koch and Dobson specify several problems experienced by the normal siblings of the retarded:⁶⁴

1. The dangers of becoming targets of excessive parental aspirations to compensate for the parental frustrations and disappointments of the retarded child are quite evident. Farber says this is experienced particularly with older boys since, when the retardate is institutionalized, the parents turn their attentions for progress onto them.⁶⁵ In the study by Grossman, certain families who had a pre-eminent awareness of the potential of their children also had a greater awareness of the limitations of the retarded child and, in some cases, the family (i.e. the parents in particular) attempted to compensate by expecting extreme achievements from the normal children.⁶⁶

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⁶⁴ Koch and Dobson, Retarded Child, p. 437.
⁶⁵ Farber, "Effects on Family Integration," P. 78.
2. The needs of normal siblings may be unmet by parents who are overwhelmed by the care required by a handicapped child. Adams says in the case of younger siblings they find it difficult to reconcile having a physically larger sibling upon whom the parents have less exacting demands. "If the older defective child receives an inordinate amount of attention . . . . there is the risk that the normal children may identify with the handicapped child in the early stages of their development and pattern their behavior on his". 67

Holt found that some of the normal siblings were extremely resentful of the attention given to the retarded child; some would attempt attention seeking devices while others withdrew from social contacts or attempted to compensate for feelings of deprivation by total absorption in their school work. He did not find, except rarely, that parental rejection of the normal child was complete. 68

3. At an early age, normal siblings have to deal with the reactions of their peers to the retarded child. This comes often at a time when they are less equipped to fully comprehend, emotionally and intellectually, the problems.


68 Holt, "Home Care," 754.
4. Sometimes guilt arises about being the normal child and glad feelings about not being the afflicted one. Watts feels sometimes siblings, "in their effort for recognition from parents, may enjoy the fact that someone else (i.e. the retardate) always gets the blame." 69 Smith states:

... many of the normal siblings will not have worked through the psychological and social strains which prevail ... These anxieties may be caused by jealousy; by resentment; by guilty feelings; and by lack of knowledge and understanding on the siblings' parts concerning what happens to their retarded brother or sister ... 70

Farber's extensive study details many factors to be considered when discussing reactions of siblings to the retardate. He concludes that they must not be considered a homogeneous group and the reactions differ in regards to sex of the normal sibling and his age relative to the age of the retarded child. For example, normal sisters exhibited more problems when the retarded child was in the home while, on the other hand, normal brothers exhibited more problems when the retarded child was institutionalized.

69 Evadean Watts, "Family Therapy: Its Use in Mental Retardation," Mental Retardation, VII (October, 1969), 42.

When the retarded child is in the home, there is more of an effect on the older sister than on the older brother and this could be a result of the fact that the older sister is expected to assume more of the maternal role in these families. Fowle duplicated this study and agreed with the findings. Ross puts forth that, besides the ages and sexes of the children in the family, the position of the retarded child in the birth order and the parental attitudes towards him will affect the reactions the normal child will have to the retarded sibling.

Some researchers feel that the normal siblings will not have problems related to the retarded child if the parents have adjusted to having a retarded child in the family. It is felt the siblings' attitudes reflect those of their parents. In fact, some authors feel that siblings can benefit from a retarded brother or sister and are not adversely affected especially when counselling is available.

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71 Farber, "Effects on Family Integration," p. 79.
73 Ross, Exceptional Child, p. 112.
Other authors, however, feel that the retardate does cause problems for the normal siblings and sometimes they are a source of continuing psychological difficulty. Problem areas for the siblings can be that they become targets of excessive parental aspirations, their needs may be unmet because of the parental demands of the retardate, and they feel guilt about being the normal child in the family; however, it is pointed out that these normal siblings must not be considered to be a homogeneous group in their reactions to the retarded child.

Although varied opinions seem to exist among researchers about the effects of one retarded child on the normal siblings in the family, the general consensus would seem to indicate that, as with the family unit, the effects are a significant factor to consider when dealing with siblings of the retarded.

Reactions to institutionalization of the retarded child

**Family reactions.** — Our intention is not to dwell on the entire issue of separation and placement per se, but to discuss the effects on the family of the institutionalization of the retarded child. Koch and Dobson point
out that "regardless of how long a family contemplates placement before acting, the placement situation critically upsets the established equilibrium in the family and new or revised coping strategies are required". 74

Eyman, et al. found that the most significant variables influencing the probability of institutionalization were characteristics of the retardates themselves. "Of the family based factors, only difficulties in supervision and care, and health problems of the patient discriminate but even these two do not show the same level of significance as the five patient characteristics". 75

Tizard and Grad suggest that families who seek institutional care for the retarded child are those who have more than one difficult child with whom to cope. 76 Grossman would attribute this in some instances to the socio-cultural status of the families in that fewer lower socio-cultural status families were able to obtain placement and thus there was an added strain placed on the family members. Grossman also indicates there is a change in the trend

74 Koch and Dobson, Retarded Child, p. 279-80


76 Tizard and Grad, "Mentally Handicapped," 117.
towards placing children in institutions; this is due in part to the realization of the negative effects placement and separation can have on the whole family. She states that the handicapped child does not always contaminate the family and require institutionalization but the impact depends on the psychological reactions of all the family members to the exclusion of the retarded child.77

When the decision for placement is made, Caldwell and Guze would suggest that these parents have a sense of solidarity as "the difficult decision about whether to institutionalize a retarded child will not be a unilateral one but one about which both parents must agree before a definite course of action is taken."78 Ross feels that making the decision for placement is often complicated by the attitudes of friends and relatives who caution the parents against "putting away" the retarded child in an institution.79

Hersh found that parents experience feelings of loss and relief after placement.80 Subsequent to the

77 Grossman, "Brothers and Sisters," 104.
78 Caldwell and Guze, "Adjustment of Parents and Siblings," 856.
79 Ross, Exceptional Child, p. 118.
80 Hersh, "Changes in Family Functioning," 99.
institutionalization, however, the parents felt freer to interact with their normal children and relieved of the guilt they may have felt for any burdens the retarded child had placed on their normal children. Dittman refers to a period of release and let-down following placement when parents become ambivalent about their decision. If things go well in the home, the parents feel they may have exaggerated the issue and feel guilty about enjoying the more settled atmosphere at home.\textsuperscript{81}

Generally, things do go well at home and better parent-child interaction emerges. Farber discovered this in his studies but, in some cases, also found the opposite to be true. In families where the retarded child had served as a "buffer" and hidden the problems, his removal initiated deterioration in the family relationships.\textsuperscript{82} Problems which had existed and been overshadowed by the retarded child now came under closer scrutiny by the parents. Incidents of problems in the family and behaviour difficulties in the other children

\textsuperscript{81}Laura Dittman, "The Family of the Child in an Institution," \textit{American Journal of Mental Deficiency}, LXVI (March, 1962), 760.

\textsuperscript{82}Farber, "Effects on Family Integration," p. 58.
had been attributed to the presence of the retardate; his removal served to highlight the difficulties actually existing in these other areas.

Institutionalization of the retarded child can cause negative effects through separation on the other family members. However, making the decision to institutionalize the retardate can pull the family members together through the bond of their common problem but this decision often causes a strain between the nuclear family and their relatives and friends.

Better relationships often result between the parents and their other children when the retardate is placed outside of the home; however, such a placement could also highlight other difficulties in the home that have been hidden previously by the problems of the retardate.

The family constellation feels the effects of the institutionalization of the retarded child - when the decision is made, when the placement is effected, and after the placement takes place. The feelings, in most cases, can be described as ambivalent for, as much as the

83 Pittman, "The Family," 761
family tries to rationalize the situation doubts about the necessity to institutionalize and the benefits to both the retarded child and the other family members as a result of this will continue to linger.

Sibling reactions.-- Farber states that, with the institutionalization of the retarded child, the sisters became freed of child-caring responsibilities thus promoting better relationships with the mother once they were not both sharing the same roles. 84 However, now that the parents were able to keep closer scrutiny on their children, the brothers felt greater pressure resulting in poorer relationships with their parents. 85

Smith, Rickets and Smith, on talking about placement, say that among the feelings roused in the siblings were "fear of placement, resentment towards the parents for placement of the brother or sister, guilt over the sibling being sent away, and envy of the placed child." 86 Dittman adds that children

84Farber, "Effects on Family Integration," p.57.

85Ibid., p. 58.

86Emily Smith, Betty Ricketts, and Sarah Smith, "The Recommendation for Child Placement by a Psychiatric Clinic," American Journal of Orthopsychiatry, XXXII (January, 1962), 45:
wonder if they also are going to be sent away and they sometimes feel that they may have caused the placement.\textsuperscript{87} Watts agrees that "children's fantasies are often focused around their being sent away from the home".\textsuperscript{88}

The reason given for institutionalization in many cases is the adverse effects the retarded child has on his siblings. Tizard and Grad found that the opposite is often true, in that siblings of children who are institutionalized were found to have greater problems than siblings where the retarded child is living at home.\textsuperscript{89}

Advice to place the child away from home in the interest of the normal children is made too routinely and often is ill-founded. True, many instances can be cited of the harmful effect of a retarded child on his brothers or sisters, but these are in the minority.\textsuperscript{90}

Hersh found that children are more adaptable to the separation than the parents and, in many cases, placement served to free the siblings to develop socially and emotionally.\textsuperscript{91}

\textsuperscript{87}Dittman, "The Family," 761.

\textsuperscript{88}Watts, "Use of Family Therapy," 42.

\textsuperscript{89}Tizard and Grad, "Mentally Handicapped," 116.


\textsuperscript{91}Hersh, "Changes in Family Functioning," 101.
A result of the institutionalization of a retarded child for the normal siblings can be a lessening of their own security in the home or guilt resulting from the feeling that they caused the need for the placement.

It is felt, however, that the children can adjust to the institutionalization easier than can their parents.

Not only is there little research on the effects institutionalization of the retarded child has on the siblings, there also is no clear consensus of opinion. It is this scarcely known area we are investigating.
CHAPTER III

METHODOLOGY

Population

The population for this study is defined as all of the families residing in the County of Essex who presently have a retarded child living at the Ontario Hospital School, Cedar Springs.

The Ontario Hospital Schools are institutions for the mentally retarded operated by the Ministry of Health of the Ontario Government. These Hospital Schools provide nursing care to those retardates who require it and they provide all types of schooling, social development, counselling and rehabilitation services to those residents who could benefit.

Children are admitted to the Ontario Hospital Schools according to the program they need and the type of vacancy which occurs. Selection of applicants is determined also on need as indicated by the 'Priority Rating Scale'.

The Ontario Hospital School, Cedar Springs, is the regional institution for retarded children that serves the sixteen counties in Southern Ontario. The
total population of Cedar Springs as of December 31, 1972 was 1,027.

As a part of its catchment area, the Ontario Hospital School, Cedar Springs, serves the families living in Essex County who have a retarded child. On December 31, 1972, 307 retardates from Essex County were in residence at Cedar Springs comprising 29.9 per cent of the total population. Forty-six of these residents were either in Cedar Springs on a short-term relief admission, usually lasting four weeks, or were on leave of absence from the institution living and working or attending schools in the community.

Essex County is the southernmost county in Ontario. The largest city in Essex County, Windsor, is an urban centre where the main occupations consist of trades, manufacturing, manual labour and service work. The county area boasts a prosperous farming community. Two-thirds of the population of Essex County live in the City of Windsor.

Essex County was chosen as our universe both because of its proximity and the convenience for conducting the study and because the largest proportion of residents at the Ontario Hospital School, Cedar Springs have their origins in Essex County.
As a preliminary to selecting our sample, we read the Hospital School files of all the residents who would satisfy the definition of our population. What we felt to be important statistical information was recorded on a form for each file read.\textsuperscript{92} There were two hundred and sixty-one residents of the Hospital School whose parents or guardians lived in Essex County as of December 31, 1972.

Sample

Most authors would agree that probability or random sampling, where every case has an equal opportunity of selection, is the method which assures the greatest representativeness and generalizability. The importance of randomness is "protection against selection bias"\textsuperscript{93} and probability sampling is most effective when the exact composition of the total group is unknown. If, however, there is information about the population already available, "investigators may prefer to choose what they

\textsuperscript{92}See Appendix I.

believe to be typical groups and examine them in detail." 94 This "purposive sampling" assumes that the investigator will be able to use his judgment to select cases while exercising a minimum of bias.

A purposive sample is often chosen for its convenience and economy. Selltiz et al., found that by including in the sample only persons with certain select characteristics, one has the advantage, in nonexperimental studies,

of disentangling . . . the independent variable in which the investigator is interested from other variables with which it is commonly associated, so that any effects that are found can justifiably be attributed to that variable. 95

The corresponding disadvantage, however, is that when one uses purposive sampling the population to which one can generalize is limited. Goode and Hatt point out that the ultimate weakness of a purposive sample is that "it does not fit the requirements of probability theory and the practical consequence is that the sample varies in unknown ways from the universe." 96


Sjoberg and Nett add that, in exploratory research, "where the investigator is intent upon formulating tenable hypotheses rather than formally testing them, or where he is searching for new ideas, a probability sampling design may not be in order." 97

With these considerations in mind, we selected a purposive sample from the available population according to our predetermined criteria.

Selection of the sample

The sample was drawn from the families of the 261 residents according to the following criteria:

1. Families where there is documented proof that another child in the family is also retarded or was diagnosed as emotionally disturbed prior to the retarded sibling's admission to the Hospital School were eliminated. In a case where there is another retarded child in the family, the siblings probably would have difficulty distinguishing the feelings they have had for each of their retarded brothers or sisters.

Since emotional disturbance in one or more children in a family is an indication of family malfunction, we would be including another variable that we

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would have great difficulty controlling. This factor was also taken into consideration by Adams in her study. Her concern, as is ours, is "not with the obviously pathological children, but with those whose problems, whatever their guise, can be seen as a normal response to a highly stressful situation ...". \(^{98}\) Thirty-six families in this category were eliminated leaving 225 families.

2. Families of those residents who were admitted to the Ontario Hospital School, Cedar Springs, prior to January 1, 1967 were eliminated. We felt that if the admission had taken place more than six years ago, there would undoubtedly be some forgetting or some distortion of the memories siblings have of the feelings they had when their retarded brother or sister was institutionalized. Since we assessed directly the feelings of the siblings around the institutionalization, this seemed to be a very important consideration.

The year 1967 was the time of the inception of the 'Priority Rating Scale', that is, a standardized scale to numerically and objectively judge each child's need for institutionalization. This scale did away with admissions to the Hospital School solely on the basis of community and political pressure, and granted admis-

\(^{98}\) Adams, "Siblings of the Retarded," 311.
to those who, on a comparative basis, needed it most.

January 1, 1967 seemed to be a natural cut-off point for our sample to ensure that we were dealing with a more homogeneous group, that is, we attempted to eliminate one extra variable. We anticipated that all the families in our sample underwent a certain amount of strain while they attempted to maintain a difficult retarded child in their home until their 'rating' was sufficiently high to warrant admission.

One hundred and fifty-eight families were eliminated for this reason leaving a total of sixty-seven families.

3. We eliminated those families where the retarded child was admitted to Cedar Springs after January 1, 1967 if he had previously had a long term admission either at Cedar Springs or in another institution. This was done because we felt that a previous admission would be an extra variable that might contaminate our sample in that the feelings of the siblings at the time of the most recent admission could either be diluted from the experience of the previous admission, or intensified if previous negative feelings had not in some way been resolved. As pointed
out by Hersh, the "family dynamics and motivation may be quite different once a family has experienced the placement of a child". 99

Furthermore, we felt it would be more difficult for the siblings to separate what they thought their feelings had been on the two separate occasions.

For these same reasons, we did not include in our sample those retardates who had been transferred to Cedar Springs from another institution.

Nine families were eliminated in this category leaving a total of fifty-eight families.

4. We did not use in our sample those cases where the child is presently, or had been, a ward of a Children's Aid Society. This eliminated the possible added factors created by dissolved families. In these cases we also could have had the difficulty of locating the siblings of the retarded child if they also had been wards of a Children's Aid Society.

We eliminated families where the mother and father had not been living together during the period of January 1, 1967 through to December 31, 1972. This eliminated families in which a divorce or separation had occurred, or one parent had died. Farber also eliminates this element from his study. As he points out,

99 Hersh, "Changes in Family Functioning," 94.
The restriction to couples married at the time of the study probably eliminated families whose integration was most affected by the presence of a retarded child. The retarded child was a factor in their divorce. The presence of the mentally retarded child may have precipitated the heart attacks which brought on the death of parents. Any conclusions of the effects of the child on family integration, when the family at the time of the study is broken by death or divorce, would be highly speculative.

In this category nineteen families were eliminated which left thirty-nine families.

5. We eliminated those families where the siblings were less than seven years of age at the time of the retarded child's institutionalization. This decision is supported by Caldwell and Guze who state that those children "who were so young at the time the retarded child was institutionalized . . . might have essentially no knowledge of the total situation and of their sibling's retardation." 101

The age of seven is "an assimilative age" when children begin "relating new experiences to old". 102 Children become more aware of others, including their siblings, at this age and their "interest in and feeling for family is very strong". 103

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100 Farber, "Effects on Family Integration," p. 28.

101 Caldwell and Guze, "Adjustment of Parents and Siblings," 847.


103 Ibid., 348.
"Verbal or cognitive intelligence is based on practical or sensorimotor intelligence which in turn depends on acquired and recombined habits and associations." 104 This reflex thinking develops to the point where, at the age of seven, children become more deductive in their thinking. They become more objective and analytical, and their thinking is very similar to that done by adults.

By excluding those children who were less than seven at the time of the retarded child's admission, we eliminated two more families leaving a total of thirty-seven.

6. Families in which there were no children in the family other than the retarded child were eliminated. Four families were excluded for this reason leaving thirty-three families.

7. One family which had moved out of the county was eliminated leaving thirty-two families.

8. The Hospital School requested that one family not be contacted for personal reasons. This left a total of thirty-one families.

9. These thirty-one families were contacted and two refused to participate. The sample for this study consisted of twenty-nine families.

The intent of our survey was to directly contact the siblings in these twenty-nine families. The available twenty-nine families had a total of eighty-seven children who could be contacted for information about their retarded brother or sister. When the questionnaires were returned (total 51), we were able to determine the number of siblings who were not living at home at the time of the institutionalization of the retarded child. These siblings (total eight) were eliminated from the sample since, not being in the home, they would not have first hand knowledge of the effects of the institutionalization on the family. Therefore, the total number of siblings whose information was used for analysis was forty-three.

Data collection

Our initial collection of data was the search of appropriate files at the Ontario Hospital School, Cedar Springs. As pointed out by Moser and Kalton, gathering information from documents compiled for other reasons, such as case records, could be dangerous in that content and reliability are beyond the control of the researcher. We were able to avoid being influenced by another person’s

opinion recorded in the files by making use of only statistical information.

The method we chose for the collection of data from our sample is the questionnaire. There are several advantages to consider when using a questionnaire rather than other methods of data collection. Some of those suggested by Selltiz et al.\textsuperscript{106} and by Moser and Kalton\textsuperscript{107} seemed to fit our purposes:

1. The questionnaire is less expensive, less time consuming, and requires less skill to administer.

2. It can be sent through the mail and, hence, covers a wider geographical area. This was of prime consideration to us because the older siblings in the families of our sample could have moved from the homes of their parents and be widely dispersed throughout Ontario or beyond.

3. The impersonal nature of the questionnaire assures some uniformity from one measurement situation to another. The standardization of questions for all participants also assures some degree of uniformity.

\textsuperscript{106}\textsuperscript{Selltiz et al., Research Methods, pp. 238-41.}

\textsuperscript{107}\textsuperscript{Moser and Kalton, Survey Methods, pp. 258-60.}
4. Since the respondent is under less pressure to give spontaneous answers, there is greater opportunity for considered answers with the mailed questionnaire.

5. There is the possibility that the participant will answer more personal questions provided he does not have to verbalize them to a stranger.

There are two disadvantages to a mailed questionnaire we had to consider. Firstly, all answers are final, they cannot be clarified, and there is no opportunity to supplement the answers with personal observation. Secondly, we were aware that it is not always possible to tell if the desired person completes the questionnaire or whether he gives it to someone else to answer for him.

Prior to mailing out our questionnaires, we sent letters to the parents of those families in our sample, informing them that they had been chosen as respondents for our survey. This was done primarily because we had to rely on the parents to forward our questionnaires to their children since we had no addresses for the siblings of the retarded children. Also, we felt it would be wise to prevent the parents from feeling we were ignoring them as members of the family. These letters stated that if

108 See Appendix 2.
any family did not wish to participate in our survey, they should inform us within the next week and a stamped, self-addressed postcard was included for this purpose. The letters also briefly outlined the purposes of the research and they were mailed on Hospital School stationery under the signature of the Chairman of the Research Committee of the Hospital School to ensure that the survey was being conducted with the co-operation of that institution.

One week later the questionnaires 109 were mailed to the families of the sample who had not indicated they were not willing to participate in the survey. Included were a covering letter 110 and a sample questionnaire to the parents. A questionnaire and separate covering letter 111 were enclosed for each of the siblings included in the sample along with a stamped, self-enclosed envelope for the return of the completed questionnaire. Each of these questionnaires to the siblings were sealed in a stamped envelope so that, for those children not living at home, the parents only had to address the envelope and forward it by mail.

109 See Appendix 5.
110 See Appendix 3
111 See Appendix 4
One follow-up letter,\textsuperscript{112} a short reminder, was prepared and mailed two weeks after the mailing of the questionnaire to those families where some siblings had not yet replied.

\textsuperscript{112}See Appendix 6
CHAPTER IV

DATA ANALYSIS

Location of population

The population for this study is defined as all of the families residing in the County of Essex who, as of December 31, 1972 had a retarded child living at the Ontario Hospital School, Cedar Springs. This population consists of 245 families who have a total of 261 children residing at the Hospital School. Of the 245 families, 169 live in the City of Windsor. The remaining 76 families reside in the county area, that is, Essex County exclusive of Windsor and its suburbs. The ratio of families in our population living in Windsor to those living in the county area is 2.0:1.

In our sample of 29 families, 21 live within Windsor while the remaining 8 live in the county area. The ratio of families in our sample living in Windsor to those living in the county area is 2.6:1.

The ratio of our sample approximates the ratio of our population and we therefore consider our sample to be representative of our population in terms of the area, the
is Windsor or the county, in which the families live. These figures would suggest that the difference in ratios is not sufficiently large to distort the results of our study considering the variable of the residence of the families alone.

Sex

The number of siblings in our sample is 87, made up of 36 males and 51 females. The ratio of females to males in our sample is 1.42:1.

The number of questionnaires returned, not including those children who were not living at home at the time of the retardate's admission to the institution, is 43. These were received from 19 males and 24 females. The ratio of females to males answering our questionnaires is 1.26:1.

There is little difference in these ratios and the sexual division of the siblings returning the questionnaires seems to be representative of the sexual divisions of the siblings in the sample. These findings suggest that the results of our data analysis will not be distorted on the basis of the sexual division of our respondents.
Age

The average age of our 43 respondents at the time of their retarded sibling's admission to the Hospital School was 11.8 years, ranging from 7 to 21 years. Their average age at the time they answered our questionnaires was 14.9 years, with a range of 7 to 26 years.

Since more than 50 per cent of the siblings responding to our questionnaire were more than 11 years of age at the time of the institutionalization, this would suggest that these respondents were of an age to be sufficiently aware of the situation in the home with the retardate to give valid responses. Since more than 50 per cent of these siblings are presently more than 14 years of age, this would suggest that, considering age only, the respondents are of a sufficient age to answer the questionnaires adequately.

Education

The questions in section two of our questionnaire were intended to ascertain changes that occurred in the siblings' school performance relevant to the time of the admission of the retardate to the Hospital School. The siblings were asked to state not only those times they had failed but also the times when they had done better or worse in school.
Of the 43 completed questionnaires received, only 41 have answers to this section sufficiently completed to be used in our analysis. Of these 41, 11 did not state they had ever experienced any change in school progress.

Nine answers were excluded from analysis in this section since the changes they indicated had taken place in school performance did not occur relative to the time of admission of the retarded. In each case, improvement and decline in school progress both occurred sufficiently prior to or following the date of institutionalization to exclude placement as a factor.

In grouping the changes in school performance for the remaining 21 respondents, we categorized the changes as being either for the better or for the worse.

Three categories are included in the division that connote changes for the better or improvement in school performance. These are:

Firstly, those respondents who replied that they had done better in school at the same time or after the admission but did not actually state they had ever done worse. We are presuming that a statement of school improvement at a certain time indicates that the respondents had not been achieving at this level previously, and therefore, a change for the better had occurred. The total of respondents for this group is 4.
Secondly, those respondents who stated they did worse in school prior to the admission but did not actually state they had ever done better. The assumption here is that a statement of poorer school performance previous to the admission date of the retardate connotes some improvement at a later date, and therefore, a change for the better has occurred. The total of respondents for this group is 5.

Thirdly, those respondents who stated they had performed both better and worse in school and indicated by their answers that the change was an improvement rather than a decline. This grouping included those who stated they did worse in school before or at the same time as the admission and better after, and those who stated they did worse before and better at the same time as the admission. The total for this group is 6.

Two categories are included in the division that connote changes for the worse or decline in school performance. These are:

Firstly, those respondents who stated they did worse in school after the admission of the retardate but did not actually state they had ever done better. The assumption here is that a statement of poor school progress after the admission date of the retardate
indicates some level of higher achievement at an earlier date and the sibling can therefore be considered to have experienced a change for the worse in school performance. The total of respondents for this group is 4.

Secondly, those respondents who stated they did both better and worse in school and indicated by their answers that the change was a decline rather than an improvement. These answers included those who stated they did better before the admission date and worse at the time of admission, or those who did better at the same time as the admission but did worse after the admission. The total for this group is 2.

The above categorizations illustrate that 21 of the admissible 41 responses were indicative of changes in the school progress of the siblings relevant to the time of admission of the retarded child. The 21 reported changes in school progress can be broken down into 15 changes for the better and 6 changes for the worse.

The fact that 51 per cent of the respondents experienced a change in school performance relevant to the date of institutionalization of the retarded sibling would suggest that this institutionalization does have an affect on the school performance of the normal siblings.
The fact that 71 per cent of the changes in school performance were improvements suggests that the institutionalization process alleviates some pressures for the normal siblings that could have been affecting their school progress.

Although the alleviation of pressures for the normal sibling by the institutionalization of the retarded child coincides with school improvement for the majority of these respondents who indicate a change in school performance, this improvement is not seen to be maintained. The incidences of changes for the better were highest during the school year of the admission up to the school year following. The sharp decline and return to the level of performance that had occurred one year prior to admission indicates pressures may return to the normal sibling once the initial relief resulting from the placement of the retarded has subsided.

Figure 1 illustrates the 12 incidences of the siblings' improvement in school performance relative to the date of admission of the retarded.
INCIDENCES OF IMPROVEMENT IN SCHOOL PERFORMANCE RELATIVE TO DATE OF ADMISSION

FIGURE 1

Of the 21 reported changes in school performance, 4 respondents stated they did only better and did not state they had done worse at a time in their school career. Eight others replied they had done better at some time in school as well as worse.

For some of the respondents, institutionalization of the retarded child corresponded to an improvement in school performance. The greatest number of responses indicating incidences of doing worse in school also occurred during the school year of the admission.
Figure 2 illustrates the 17 incidences of the siblings decline in school performance relative to the date of admission of the retardate.

\[ \text{Graph showing number of responses over number of years before and after admission.} \]

**INCIDENCES OF DECLINE IN/SCHOOL PERFORMANCE RELATIVE TO DATE OF ADMISSION**

**FIGURE 2**

Of the 21 reported changes in school performance, 9 respondents stated they did only worse and did not state they had done better at a time in their school career. Eight others replied they had done worse at some time in school as well as better.
Figure 2 shows a greater incidence of doing worse in school prior to and including the school year in which the admission took place. The incidence of doing worse declines sharply during the year following admission but begins to increase again the second year after the admission has taken place.

These results would suggest that the institutionalization of a retarded child does affect the school performance of the normal siblings, whether it be for the better or for the worse, since the highest incidences of change occur during the school year in which the retardate was admitted.

Involvement in decision making

The questions of who made the decision to institutionalize the retarded child and whether the sibling agreed with this decision were asked to determine if the siblings had been involved in the decision making process. Of the 43 completed and returned questionnaires, only 42 contained sufficient information to be included in our analysis. Of these 42, 6 or 14 per cent did not remember who had made the decision.

Of the remaining 36 respondents, 10 or 28 per cent stated that the parents exclusively were involved in the
decision making. Nine or 25 per cent said that the
decision was made outside of the family by doctors and/
or social workers.

Seventeen or 47 per cent of the respondents
replied that the family unit was involved in some way in
making, or at least discussing, the decision. Thus,
53 per cent of those who remembered the decision maker
felt that they themselves were not included in this
process.

In spite of over half not being included, only
1 of the 36 siblings did not agree with the decision to
institutionalize. One other sibling who could not
remember who made the decision also disagreed with it.

In order to determine whether the siblings
had been involved at the time the decision to
institutionalize was made, the following questions were
asked: "When was this decision made?" and "When were you
told about this decision?" Of the 43 respondents, only
26 gave sufficient information to be analyzed.

Twenty-two or 85 per cent felt that they were
told about the decision right at the time the decision
was made. Fifteen percent of the remaining 4 respondents
felt they were told after the decision had been made.
Of the 22 who were told at the time the decision was made, 17 or 77 per cent stated this was prior to the actual date of the admission. These answers ranged from 9 who knew one or two months prior to the admission to 8 who knew more than one year before the actual admission. The remaining 5 or 23 per cent who were told at the time the decision was made stated that this was also at the time the admission took place. It would appear that only the 8 who knew of the decision to institutionalize a year or more before the admission were actually involved to any extent in this process since the application and pre-admission procedures take considerably more time than one or two months before the admission date.

Comparing the responses of these 8 to the question about the decision maker, even though only 2 of these 8 were involved in discussing or making the decision with their families at the time they felt the decision was made, they were informed of the decision sufficiently ahead of the time of the admission to warrant our statement that they did play some role in the plans being made for their retarded sibling.

The responses in this section would suggest that the majority of siblings were neither involved in nor aware of the plans being made for their retarded sibling to any extent.
Involvement in admission procedures

We asked whether the siblings accompanied their retarded brother or sister to the Hospital School on the date of the admission in order to determine if the siblings were included in the admission procedures.

Of the 42 responses to this question, only 6 stated they had accompanied their brother or sister on the admission day. Only 2 of these 6 spoke with professional staff at the Hospital School. It should be noted that the children who accompanied the retarded child ranged in age from 7 to 15 with 4 of the 6 children being over the age of 12 which would indicate they were of a sufficient age to be more actively involved in the procedures once they were at the Hospital School. There are no regulations at the Hospital School which prohibit Social Workers from consulting siblings.

These results suggest it was not a practice of families to include the siblings in the admission procedures at the institution. It is also noted that in no instance did a complete family unit accompany the retarded child on the day of admission.

Explanations of the institutionalization given by the siblings

The question asking how the siblings explained to their friends the reason for the institutionalization was
included in the questionnaire because we felt that the ability and freedom to explain would give some indication of their understanding and acceptance of the situation.

Of the 43 respondents, 39 gave sufficient information to be analyzed. These respondents often offered more than one answer so that the following percentages will add up to more than 100 per cent.

Of the 39, 7 or 18 per cent of the respondents seem to have avoided discussing the institutionalization of their sibling with their friends by replying to this question that they do not know what they said, they kept it to themselves, or they did not tell anyone.

Five or 13 per cent of the respondents indicated that they felt their friends already knew of the placement and there was no need for further explanation.

Twelve or 31 per cent of the responses indicated that the siblings told the facts about the circumstances surrounding their brother or sister's admission to Cedar Springs. Ten or 26 per cent of the 39 stated that the reason they gave to their friends for the institutionalization related to problems within the family, and 21 or 54 per cent of the 39 stated they told friends the admission was a result of problems of the retardate.
The results would suggest that the majority of the siblings were able to handle the explanation of the admission adequately and offered answers which indicate some understanding of the problems that had existed in the home with the retardate.

All of the answers for this question are illustrated in Table 1.

Contact with social agencies

This question was asked in an attempt to determine whether siblings had difficulties that required assistance from agencies in the community and, if so, how the time of these contacts related to the date of the institutionalization of the retarded child. Only 1 person answered this question indicating they had had contact with an agency for assistance directly related to problems associated with the retarded child.

Since this was the only item of the questionnaire that nearly all of the respondents did not answer, the possibilities exist that there was in fact no contact, or the question was of too threatening a nature and the respondents did not want to disclose this information. Unfortunately, there was no space for the respondents to indicate they had not had any contact so that we are not able to verify either of our assumptions.
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**Explanations Given To Friends**

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66
Opportunities to discuss concerns about admission

We asked whether the siblings talked to anyone about how they felt when the retardate was institutionalized to discuss these feelings. Forty-two of the respondents gave sufficient information to this question to be analysed.

Of the 42 who answered the question, 7 or 17 per cent talked only within the family while another 14 or 33 per cent talked both within the family and with someone outside of the family. That is, exactly half of the respondents relied primarily on the family unit to discuss their feelings.

Seven or 17 per cent of the responses indicate that the siblings talked only with someone outside of the family. Fourteen or 33 per cent of the respondents talked with no one. Of these 14 who talked to no one, 6 did not answer whether they wanted to talk to anyone, 4 said that they did want to, and 4 said they did want to, and 4 said they did not want to talk to anyone.

Of the 33 people who did talk to someone, only 3 of these respondents found their talks not helpful.

There do appear to be some trends in family groupings about discussing their feelings. There were
14 families that had more than one child responding to this question. In 10 of these families the children concurred in their answers, for example, 1 family talked amongst themselves, 4 families talked amongst themselves as well as with others outside of the family, and 5 families primarily talked to no one although a few of the children may have talked to outsiders. In each of the remaining family groups, no 2 siblings concurred in their answers.

With 50 per cent of the respondents relying on their families to discuss their feelings and 33 per cent of the respondents talking to no one, this would suggest that professional assistance was not used by the siblings at the time of the retardate's admission to the Hospital School. The trends in family groupings further suggest that the siblings' methods of dealing with their feelings about the retardate's institutionalization remain fairly consistent within the family units.

The answers to the questions "Did you talk to anyone . . . ?", "Did you find these talks helpful . . . ?", and " . . . do you think it might have been helpful if you had?", are illustrated in Table 2.
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Changes in family relationships

We asked the siblings if they felt family relationships altered after the institutionalization of the retarded child in order to determine if changes occurred within the family unit associated with the admission.

Forty of the respondents gave sufficient information for analysis. Fifteen of the 40 stated that there were no changes in family relationships. The remaining 25 all described changes that can be considered to be improvements in relationships and the home atmosphere.

There were 13 family groupings where more than one child responded to this question and in 10 of the 13 families, the sibling members concurred in their answers to whether there was a change in family relationships. In the remaining 3 family groups the siblings did not agree in their answers.

This information would suggest that the admission of the retarded child to the Hospital School was associated with positive changes in the relationships of the other family members in the home.

The information collected for this question is presented in Table 3.
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The siblings' feelings at the time of admission

The siblings were asked to state how they felt at the time of their brother or sister's institutionalization. Thirty-eight of the respondents gave answers sufficient for analysis and each of these usually gave more than one response.

There were 28 different responses to this question and these were grouped into 3 different categories. The following are the 3 categories:

1. Sad -- Twenty-nine of the respondents stated they felt sad at the time of the admission.

2. Missed -- This category includes the answers that indicate the respondent missed his retarded sibling, felt a loss, felt empty, wished the retarded sibling could come back home, felt hurt, and was depressed. Fourteen responses were included in this category.

3. Contented -- The answers grouped in this category include feelings of happiness, relief, optimism, they were sure and satisfied with the care the retardate would be receiving, glad another sibling was relieved of the care of the retardate, and felt that the household was more relaxed. There were 21 responses included in this category.
4. Anxious -- Grouped here are the statements of experienced feelings of anxiety, worry, distrust, nervousness, and they were unsure, mixed up, upset, and felt pressure. Eleven siblings gave such answers.

5. Guilty -- Two respondents felt guilt over the retardate's institutionalization.

6. Best for the retardate -- Twenty-two of the siblings felt the admission was the best thing for their retarded brother or sister. Responses here included feelings that it was best for the retardate, he would receive proper care at the Hospital School, he would have an opportunity to learn, and he would be with other children like himself.

7. Mad -- One sibling stated he felt mad about the institutionalization of the retardate.

3. Mixed feelings -- One respondent stated he had mixed feelings about the admission to the Hospital School.

Sadness and relief were the 2 single feelings most often expressed by the respondents. Forty-two or 41 percent of the total of 102 responses were composed of these 2 specific feelings. Twenty-three percent of the responses indicated that the sibling felt institutionalization was the best thing for the retarded child so that he could receive proper care and training; this could be interpreted as an attempt to justify their own feelings by emphasizing the benefits of the admission for the retardate.
The information given by the respondents for this question is illustrated in Table 4.
### Table 4

**Siblings Feelings at the Time of Admission**

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CHAPTER V

Discussion of findings.

The majority of the subjects in our study were not involved in the planning stages nor in the implementation of the institutionalization of their retarded siblings. The procedures necessary for admission of a retarded child to the Ontario Hospital School, Cedar Springs, involve assessment interviews, obtaining family histories, and counselling sessions which, along with the waiting period necessary for the availability of a suitable bed, at the Hospital School, involve several months and sometimes years before the actual placement can be effected. The siblings have not been actively involved in these procedures. Since the professional services provided for the retardate and the parents were not available to the siblings, they have had to rely on other family members for any discussions or explanations.

Most families have not included the siblings in the procedures on the day of admission. There could be many practical reasons why this is not the practice such as the travelling distance, lack of car space, and the necessity to take time off school, but from some of the siblings' comments on the questionnaires, they would lik
to be included so that among other things they could see the type of setting in which their brother or sister will be living, and the kind of care and training he will be receiving.

Our results indicate that the institutionalization process has some effect on the siblings' school performance. This is shown by the greater number of changes in school progress around the time of the admission of the retarded child. The majority of changes in school performance were improvements but these improvements were not maintained. The changes in family relationships following the institutionalization were positive in the majority of these cases. These two factors considered together would suggest that there is something lacking with which to maintain the individual adjustment of the siblings.

When one considers the lack of involvement of the sibling in professional counselling services and his reliance on other family members for discussion around the institutionalization, one could conjecture that the resources of the family in this instance are not adequate and there is a need for siblings to receive additional assistance from outside services in order to maintain their initial improvements after the admission of the retarded child.

As outlined in Chapter 1 of this study, a
change in the family composition will upset the family homeostasis and will necessitate an alteration of roles in order to achieve a new balance. The answers given by some respondents that there were no changes in family relationships following the admission are not consistent with current data available in the field of family therapy.

Therefore, these particular answers would suggest that these respondents were not able to recognize and/or deal with changes that had occurred in the area of family relationships. It might suggest that there was an element of denial on the part of the siblings. The siblings may not be permitting themselves to see any changes in familial relationships.

The question of denial on the part of the siblings is raised because there are indicators, such as the 'Priority Rating Scale', which show that there were problems between the siblings and pressures on the family prior to the admission. The 'Priority Rating Scale' for admissions used by the Ontario Hospital Schools includes two items related to the siblings of the retarded child. These are the "familial demand of other siblings" and the effect of the retardate on "sibling relationships". The purpose of these two items in the rating scale is to point out problematic behaviour and we have analysed these two items to check the reliability of the answers of the siblings.
Fourteen of the fifteen siblings who stated there were no changes in family relationships obtained high scores on these two items which indicates considerable problems in these areas. It is unlikely that there would be no changes in family relationships with the removal of the retardate from the home and one could conjecture that these respondents have been unable to deal with this question. The other possibility is that the undesirable situation in the home has indeed not changed and one could conclude that these families could have a need for assistance to effect improvement of the situation.

The majority of our respondents did seem able to accept the retardate's institutionalization. Both in their explanation to friends and in the expression of their feelings about the admission, they emphasized that they thought institutionalization was the best thing for their brother or sister. The overwhelming majority stated they were sad but relieved at having the sibling admitted to the Hospital School and they comforted themselves by considering the greater benefits that awaited the retardate in the institution. Again, their comments indicate that the siblings seem to be more comfortable with the institutionalization when they had an opportunity to visit their brother or sister and see for themselves the improvements that were being made.
The recent trend in the field of mental retardation, as outlined in the White Paper published by the Ontario Government, is the maintenance of the retarded in and/or their return to the community rather than isolating them in large government institutions. The comments of the respondents often stressed their appreciation of having such a place as the Hospital School available for the retarded child and they feel the retardate should be with others like himself. It would seem that the siblings' acceptance of the retarded child is based, to a large extent, upon the retardate's removal from the home to receive care and training. If this is leaving the retardate in or returning him to the home or proved to be upsetting to the siblings and may alter the siblings' acceptance of their retarded brother or sister.

In summation, the findings of our survey indicate that the siblings of the retarded have not been involved in the planning and placement of the retarded child. There is some evidence to suggest that they experience difficulties in their personal adjustment at the time of the admission but they are generally accepting of this institutionalization as the best thing for the retarded child.

Limitations of the study

The major limitation in our study was the use of a questionnaire as the method of data collection. As mentioned in Chapter Three, a personal interview method may have been more beneficial in obtaining the types of answers we wanted concerning the reaction of the siblings to the institutionalization of the retarded child. It also would have assured that the designated subject gave his own responses and provided an opportunity for clarification of responses. We realized, however, that some of the siblings may now be out of the home or even out of the county and the time and cost involved would have prohibited conducting personal interviews.

The rate of our returns may have been affected by our reliance on the parents to forward the questionnaires to the siblings. However, this was our only recourse as we had no other method of determining where the siblings were now living.

Conclusions

Our survey leads us to conclude that the siblings of the institutionalized retarded child have not had the benefits of the professional services that are provided for the parents and the retardate. These siblings do have needs that are not being met and as a result their personal adjustment is being affected. We recommend that
families and social workers involve the siblings more actively in the planning and implementation stage of the retardate's institutionalization. In fact, we suggest that the siblings could benefit from involvement in all areas of planning for the retarded child.

Many authors have highlighted the need for research in the area of siblings of the retarded. Our exploratory study has shown some sibling reactions to the institutionalization of the retarded child which warrant further investigation. It would be beneficial for experimental studies to be conducted comparing the reactions of the siblings to those of the siblings of retarded children who have not been institutionalized.

As a result of our study, we hypothesize that the exclusion of siblings from the planning and implementation of the institutionalization of the retarded child results in difficulties in personal adjustment for the siblings.
CHAPTER VI

SUMMARY

This exploratory study was undertaken to determine the effects that the institutionalization of a retarded child in the family has on the siblings. The basic premise was that if children are excluded from the planning for the retarded child about to be institutionalized, some difficulties could arise in the acceptance by the siblings of the retardate's admission. The purpose of this study was to determine whether siblings are affected by the retardate's institutionalization and whether there is a need for social work services in this area.

The sample for the study consisted of twenty-nine families residing in Essex County who had a retarded child at the Ontario Hospital School, Cedar Springs. This involved eighty-seven siblings over the age of seven at the time the admission took place. Questionnaires were mailed to these siblings and fifty-one completed questionnaires were returned, forty-three of which were used in the analysis.

The analysis of the data concentrated on three main areas:
On the basis of school performance, there is evidence that the institutionalization process has some effect on the siblings. Half of the respondents in this study experienced a change in school performance relevant to the time of admission of the retarded child.

It was also found that the majority of respondents were not involved in the planning stages nor in the implementation of the institutionalization of the retarded sibling.

Further, it was found that the respondents seemed to be accepting of the retarded sibling's admission, but there is some evidence available to indicate that the responses may have been denial reactions. As such, the siblings may not be as accepting of the institutionalization as their responses indicate in the first analysis.

The results of the data analysis lead to the conclusions that institutionalization of the retarded child in the family does have an effect on the siblings. Changes both in the school performance of the siblings and in family interaction, and the sadness followed by relief felt by the siblings after the admission had taken place support the effect the removal of the retarded child has on the siblings. There appears to be evidence that the siblings are affected by the institutionalization process but the study also points out the lack of any services
for the siblings that will fill the needs they experience.

Recommendations are posited that siblings be more actively involved in the family unit when planning for the retarded child takes place. The siblings should also be more involved by social workers who are dealing with the parents and the retarded child.

It is further recommended that further research be conducted to determine the extent to which siblings are affected by the institutionalization of the retarded child in the family.
APPENDIX 1

STATISTICAL SHEET

NAME: ____________________________________________

Casebook #: ___________________ Word: ___________________

Date of Birth: ___________ Date of Admission: ___________

I. O. __________________ Taper: Long, Short

kist: ____________________________________________

A. A. M. D.: _______________________________

Last admitted from: ________ Previous admissions: (place, date)
________________________________________________________________

CONTACT: ________________________________ ________________________________
(name) (address) (phone)

Mother: ___________________ Father: ___________________

natural: ___ step: ___ natural: ___ step: ___

foster: ___ dead (date): ___ foster: ___ dead (date): ___

out of home (date): ___ out of home (date): ___

SIBLINGS: (name) (d.o.b.) (sex) (relationship) (whereabouts full, step) at admission

1. ________________________________________

2. ________________________________________

3. ________________________________________

4. ________________________________________

5. ________________________________________

6. ________________________________________

RATING SCALE: score: ______ date: ______

Score for "familial demand of other siblings": ______

Comments: __________________________________________

Score for "sibling relationships": ______ Comments: ______

________________________________________________________________

88
Dear Parents:

In keeping with our desire to provide improved services to the children and families we serve, we ask your co-operation as participants in a research survey presently being conducted by the School of Social Work at the University of Windsor in conjunction with the Ontario Hospital School, Cedar Springs.

Within the next week, letters will be mailed to many of the brothers and sisters of the residents at the School. These letters will contain questionnaires that will ask certain questions of your children important to the research being carried out. Only those children who were seven years of age or older at the time their brother or sister was admitted to Cedar Springs will be contacted.

We urge your assistance. You will receive a letter containing a number of the questionnaires, each in a separate, stamped envelope. When the letters arrive, will you please ensure that your children receive their appropriate copies. The envelopes will have your child's name on it so that, for those children not presently living at home, you need only add their address to the envelope and forward it.

We will enclose a questionnaire for you to read but please do not help your children with their answers. It is very important they give their own replies.

If there is any reason why your children do not wish to take part in this research project, please sign and mail the enclosed postcard within the next week and we will respect your wishes.
Dear Parents:

Thank you for agreeing to take part in our research survey.

As outlined in our first letter, we are seeking responses from some of the brothers and sisters of children residing at the Ontario Hospital School, Cedar Springs. This is being done in an effort to investigate the need for improved services to the families of the residents.

We have enclosed a separate questionnaire for each of your children. For those children not presently living at home, would you please address and mail the questionnaire to them. There is a stamped, self-addressed envelope for the return of each completed questionnaire.

Also enclosed is a copy of the questionnaire for your use. We would appreciate any comments you, as parents, would like to make concerning it or any other part of the survey.

Again, we would like to stress that it is important for each child to complete the questionnaire on his own, as we are seeking each individual's response. The replies we receive will be strictly confidential and the questionnaires will be seen only by the researchers. No names, addresses, or other identifying information will be used in our reports.
If you or your children have any questions, please feel free to contact us by writing or at the following number in Windsor 256-6479.

We appreciate your interest and co-operation in our research survey.

Sincerely yours,

C. Pamela Ayland

Gordon Markham
Research Co-ordinators
Dear

We are making a study of families of children at the Ontario Hospital School, Cedar Springs. We hope you will help us by answering some questions. This survey is being done by the School of Social Work at the University of Windsor and the Ontario Hospital School, Cedar Springs.

We have mailed letters to many parents of children who are now at Cedar Springs. In them were pages of questions to be given to the brothers and sisters of the children in the Hospital School. When you receive the questions, please answer them and return them to us in the stamped envelope which is enclosed.

We are interested to know the answers each child in the family will give. Your answers will help us in our study to understand how we can better assist the families of the children at Cedar Springs.

Your brother or sister may have been at the Hospital School several times. We are interested in your thoughts and feelings when your brother or sister most recently entered the Hospital School.
Your answers to our questions will be seen only by the two researchers. No names, addresses, or other identifying information will be used in our reports.

If you have any questions, please write to us at the address on the stamped envelope, or telephone us in Windsor at 256-6479.

We hope to receive your answers to our questions as soon as possible.

Thank you for assisting us with this study.

Sincerely yours,

C. Pamela Ayland

Gordon Markham
Research Co-ordinators
APPENDIX 5

QUESTIONNAIRE

1. a) What is your name? ___________________________ (first) ___________________________ (last)
   If married, give your maiden name: ___________________________

   b) Sex: male / / female / /

   c) Date of Birth: ___________________________ (day) ___________________________ (month) ___________________________ (year)

   d) What is the name of your brother/sister who presently is residing at the Ontario Hospital School, Cedar Springs?

   e) What was the approximate date your brother/sister was admitted to the Hospital School on a long-term basis? ___________________________ (month) ___________________________ (year)

   f) Was your brother/sister living at home up until the time he/she was admitted to the Hospital School?
      yes / / no / /

   g) Were YOU living at home at the time your brother/sister was admitted to the Hospital School?
      yes / / no / /

   h) Please list everyone who was living in your parents home at the time your brother/sister was admitted to the Hospital School. For each person, tell what their age is NOW and state whether they are male or female:

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2. EDUCATION
a) Are you NOW attending school? yes /\ no /\?
   If your answer to a) is YES, that is, if you presently are attending school, answer sections b) to h):

b) What is the name of your school? ____________________________

c) What are the names of other schools you have attended?
   ____________________________________________
   ____________________________________________
   ____________________________________________

d) What grade are you in? __________
e) Have you ever repeated a grade? yes /\ no /\?
   If YES, what grade did you repeat? ____________________________

f) Have you ever had to be absent from school for more than a one month period of time? yes /\ no /\
   If YES, when did this happen? (month) (year)
   to (month) (year). What were the reasons for this absence? ____________________________

   ____________________________

g) Has there ever been a time when you did better in school than you usually do? yes /\ no /\
   If YES, what grade were you in when this happened?
h) Has there ever been a time when you did worse in school than you usually do?  yes /\  no /\  
If YES, what grade were you in when this happened?  

If your answer to a) is NO, that is, if you presently are not attending school, answer sections i) to o):

i) What are the names of the schools you have attended?  

j) What is the last grade you completed?  
k) Did you ever repeat any grade?  yes /\  no /\  
If YES, which grade did you repeat?  
l) Did you ever have to be absent from school for more than a one month period of time?  yes /\  no /\  
If YES, when did this happen?  
\(\text{month)} \quad (\text{year})\quad \text{to} \quad (\text{month)} \quad (\text{year})\  
\text{What were the reasons for this absence?}  
m) Was there ever a time when you did better in school than you usually did?  yes /\  no /\  
If YES, what grade were you in when this happened?  
n) Was there ever a time when you did worse in school than you usually did?  yes /\  no /\  
If YES, what grade were you in when this happened?  
o) Why did you leave school?  
\[\text{Reasons:}\]
3. a) Do you remember who decided that your brother/sister should be admitted to the Hospital School? Please check the appropriate box:

- mother
- father
- both parents
- whole family
- doctor
- social worker/counselor
- other (please state who):
- I don't remember who made the decision.

b) When was this decision made? ____________ (month) (year)

c) When were you told about this decision? ____________ (month) (year)

d) What did you think of these plans?

- I agreed with the plans.
- I did not agree with the plans.

e) Who took your brother/sister to the Hospital School on the day he/she was admitted? ____________

f) Did YOU go to the Hospital School on the day your brother/sister was admitted? yes / / no / / If YES, did you talk to anyone at the Hospital School?

- doctor
- social worker
- secretary
- residential staff
- other (please state who): ____________
- I don't know who I talked to.
- I didn't talk to anyone.

If you did talk to someone, did you find this talk helpful to you? yes / / no / /
g) How did you explain to your friends about your brother/sister being admitted to the Hospital School?


4. a) The following is a list of social service agencies serving the residents of the City of Windsor and the County of Essex. Would you please place a check mark in the box beside the names of any agencies with whom you have had contact. Also, please give the month and year when you began contact and the month and year when you ended your contact.

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Describe briefly the reasons for your contacts with the above agencies: ________________________________

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b) Did you talk to anyone about how you felt or about concerns you had when your brother/sister was being admitted to the Hospital School? yes __/ no __

If YES, please check to whom you talked:

/// mother
/// father
/// sister
/// brother
/// other relative
/// friend
/// priest or minister
/// teacher
/// Big Brother/ Big Sister Organization
/// Probation Officer
/// Social Worker/ Counselor
/// Other (please specify): ________________________________

Did you find these talks helpful to you in sorting out your feelings about your brother/sister being admitted? yes __/ no __

If you did not talk to anyone about your feelings and concerns when your brother/sister was admitted to the Hospital School, do you think it might have been helpful if you had? yes __/ no __
c) Do you think the relationships between different members of your family changed in any way after your brother/sister was admitted to the Hospital School?  yes / / no / / 
If YES, what changes do you think took place?

________________________________________________________________________
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d) When a child is admitted to a Hospital School, the family members usually have mixed feelings. Please state, to the best of your memory, all of the feelings you had when your brother/sister was admitted to the Hospital School (for example: nervous, relieved, sad, contented, dissatisfied, etc.):

________________________________________________________________________
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________________________________________________________________________

Are there any additional comments you would like to make?

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THANK YOU FOR YOUR CO-OPERATION. PLEASE RETURN THIS COMPLETED QUESTIONNAIRE IN THE SELF-ADDRESSED, STAMPED ENVELOPE WHICH HAS BEEN PROVIDED.
SELECTED BIBLIOGRAPHY

Books


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**Journals**


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