

The Signal



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by David Lonie, MD

For the last six years I have been the liaison child psychiatrist with the Liver Transplant Team at the Children's Hospital in Sydney, a team that until recently carried out most of the liver transplants on children under the age of 5 in Australia. In this team I work very closely with the Social Worker, Diana Carmody. During the time I have worked with the Team, 58 children and adolescents have been assessed. Forty of them have been under the age of 5 with the vast majority being under the age of twelve months at their first assessment. It is my experience with these young children I would like to share in this article.

The team is under the direction of a pediatrician rather than a pediatric surgeon, which is unusual. It is, however, one of the strengths of this particular team, as it emphasizes the place of the actual transplant procedure (if it takes place) within the context of the overall management of the child and the family, rather than making the transplant the central concern. Since the conditions which lead to a child's assessment for liver transplant are usually chronic rather than acute illness, the overall care of the family is of great importance.

Although the land mass of Australia is almost the size of the United States, the population is only 18 million. The distribution of the population is very skewed so that the greatest concentration of people live on the eastern and southeastern seaboard, with the major population centers being less than two hours from each other. While theoretically our patients could come from a very large area indeed, there were only a few who lived more than two hours by plane from us. For reasons which I will try to explain later, this did mean considerable dislocation for the families.

Because the family, or at least the parents, are expected to be available to the child during the period of hospitalization, an important aspect of the facilities is accommodation for the parents and families, particularly around the time of the transplant and postoperative period. Fortunately, a number of rooms are available in a home close to the hospital ward. The accommodation, once used to house nurses, is sparse—one large room partially divided into a small living area, and a slightly larger sleeping area.

There are five rooms in all with a kitchen where the parents can prepare meals. At any one time, there are likely to be two families from the transplant program in the units.

The aim of facilitating the parent's contact with their sick child is to reduce the effect of the separation as a stressor both for the child and for the parent. Encouraging closeness over the period the child is severely ill postoperatively is not without its hazards. At times a complex group

Liver Transplantation and Young Children An Australian Perspective

dynamic develops in the Units, particularly when one family has a child who is doing well and another has a dying child.

Geographical disruption has other consequences. Because of the long treatment period, rarely less than six months, financial problems in the families have been, in one way or another, almost invariable. With interstate families in particular, most wage earners have needed financial support from the welfare services and have not been able to find employment while in Sydney. There is therefore a "cluster" of difficulties for interstate families, or isolation families—isolation from the extended family and friends, separation from familiar surroundings, and loss of financial support. If the child dies, there are problems of finding emotional support and of feeling isolated

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from those who have shared the day-to-day challenges during the transplant period.

Assessment Process

Most of the children presenting with liver disease which may need transplant are admitted for about ten days. During this time there is a full physical work-up as well as visits to the social worker, occupational therapist and the psychiatrist attached to the team. My approach is to see the whole family wherever that is possible; this includes the parents and, depending on the circumstances, the siblings. The ten days over which the assessment takes place is a bewildering time for the child and the parents—a large number of people are involved, and it can be a very confusing and overwhelming experience. I try to see the family at least twice—at the beginning of the assessment period and then again at the end.

Transplant Procedure

When the decision is made that a transplant is indicated and the family agrees to this, the child is placed on the active waiting list. If the child is well enough to be managed as an outpatient, the family is given a long range pager with one parent expected to carry it at all times. When a suitable donor liver is available, the pager is activated and the Pediatrician in charge of the team contacts the family and arranges admission sometimes necessitating air ambulance transport. Because time is such a critical factor here—the transplant needs to take place within twelve hours of a donor liver becoming available, and the procedure itself takes an average of twelve hours—this period of waiting is extremely stressful for the parents.

Psychosocial stressors

I will consider the effects of the stress on the family under four

headings: the effect on the mother-child relationship; on the marital relationship; on the siblings and the effects of a child's death.

Effect on the Mother-Infant Relationship

As the most common illness which necessitates liver transplant is biliary atresia, most of the children we are seeing for the first time are under two years old. The developmental tasks of this period are biobehavioural organization and attachment. Biobehavioural organization refers to the ability of the infant to establish and maintain stable physiologic responses to external stresses. Biliary atresia and the resultant hepatic dysfunction in the first few months are not so severe as to compromise the development of these homeostatic mechanisms (as, for example, might happen with severe congenital cardiac or neurological disorders). With regard to the development of attachment the situation is more complicated.

The development of attachment is a dyadic process which depends on mutual synchrony and attunement. The diagnosis of a life threatening illness cuts through this process. Unlike congenital deformities obvious at birth such as cranio-facial dysostosis, the child with biliary atresia is not seen in the first few days as ill. Diagnosis is a time of crisis and the way in which the parents, particularly the mother, deals with this crisis may have long term effects on attachment patterns.

In children diagnosed with cerebral palsy, Robert Marvin has demonstrated that the mother's ability to resolve the "loss" of her percept of the normal child affects the attachment status of the child as measured in the Ainsworth Strange Situation Procedure at twelve months of age. In this study, 90% of the infants whose mothers were unable to resolve the "loss" of a perfect child, developed an anxious attachment at twelve months. Although we do not know how much

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this might contribute to later pathology, given the subsequent events which test the mother-child relationship, it is likely to be a major determinant in outcome.

Thinking about this work in relation to the children we see is leading to a change in my practice. I need to explain that the diagnosis of biliary atresia is usually made within the first ten weeks of life, and that there is a relatively simple operation that leads to good liver function in about 80% of infants. This means that children for whom this operation is successful may not need a liver transplant and if they do, it can be done at a much later time. Until recently, I was not seeing the children who needed transplant until the time of the transplant, often many months after the initial diagnosis had been made. But Bob Marvin's work suggests that it may be around the time of the original diagnosis, that is, before the child is ten weeks old, that processes are set in train which could determine the parents' attachment to their infant. Leaving intervention with the family until the time of the transplant might be running the risk of intervening too late. So I am now seeing as many infants as I can at the time of the first diagnosis, establishing a relationship with the family which I can maintain over the first few months of the child's life. Even though I know that a lot of these children are not going to need a transplant for a long time, I am hoping to be able to demonstrate that when they do, there is evidence that getting to know them from the time of the initial diagnosis improves their long term prognosis.

Normal development requires the child and the parents to negotiate the process of increasing separation. We know that a child needs a secure base in order to be able to move away and explore, and that parental anxiety or depression may interfere with this process. Fear of loss of a child makes it difficult for a parent to allow enough emotional space for the child to separate, and physical symptoms,

including those of feeling "just ill" from chronic liver failure in the child reduce the child's ability to separate emotionally from the parent. As a result, there may be a pattern of mutual dependency which over time may come to contain elements of hostility so that neither child nor parent can enjoy each other. In this situation we have made efforts to provide support for both parent and child to separate emotionally. In one such instance where a fifteen month old child and her mother were intertwined with each other to the exclusion of all other relationships including the marital one, and it looked as though the child would not gain enough weight to allow for a transplant, the psychiatrist and occupational therapist worked together in joint sessions to encourage the couple to separate. The rationale behind this was that if some degree of separation could be achieved, they might be able to have an enjoyable relationship with one another and the mother would then have some happy memories of a responsive child rather than a clingy dependent one should the child die.

The outcome was different than what we had imagined. At what seemed to be the last moment a donor was found and the child did very well postoperatively. There were still problems with the mother's anxiety about allowing anyone else to look after her child and some exclusion of the father was evident for a while which necessitated some work with the marital couple. However, when the parents left Australia to return to the country of their birth three years later, the child seemed well on her way to negotiating the problems of going to school satisfactorily, and had developed a very good relationship with her father.

Effect on the Marital Relationship

The presence of a seriously ill child in a family has a profound effect on the marital relationship. Not

surprisingly we found that a determining factor of the overall emotional effect on the family was the stability of the marital couple where there are two parents involved. At the time of the assessment, particular attention is paid to the relationship between the parents, how they have handled stress separately and together in the past, and their ability to empathize with the other in times of stress. We found it useful to think ahead and hypothesize what might happen between the couple in the postoperative period although it was hard to predict what would happen; even the most stable relationship faced with the prolonged stress of a very difficult postoperative

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course can be threatened. A particularly problematic relationship is where the couple handle stress differently, one parent becoming emotional and the other becoming non-communicative. In several cases it has been very useful to have a male psychiatrist and a female social worker and we have found ourselves working individually with the couple. In one such situation the parents stopped talking to each other, taking alternate shifts with their sick child and giving only the briefest and necessary update on the child's condition at change of "shift." Separation and divorce here looked very likely but were perhaps avoided by getting the non-communicative partner involved in activities outside the hospital on his times off—he had dealt with the threat of emotional

intimacy with his wife before the child had become sick by rather solitary hobbies, and his wife had gained her emotional supports from her friends in the small country town they came from. The child did well with the transplant, and when they returned home they were able to reestablish their old patterns which provided stability for the relationship.

Another important factor in working with marital relationships is the result of a major shift in role definitions in Australian society; there is a new willingness on the part of fathers to be more closely involved with their infants. It is relatively easy to get both parents to participate in the care of their child before and after transplant and when two parents are involved, the stress level is much more manageable. Being a single parent is no bar to transplant, but we know it is very demanding on the single parent and so think very carefully about the social supports we can arrange for the family.

The Effect on the Siblings

Over a third of the children we saw had siblings. Hospital admission and, particularly transplant, resulted in major disruption of their sibling's lives. Even when the whole family was admitted to the Units there was major disruption. School age children attended the local school but were subject to the problems that beset a new child coming into an established class. Again this disruption was most significant for children who had come from other centers, but even in local families where the family life went on seemingly as before except that the mother and patient were absent from the home for prolonged periods, the siblings exhibited distress, confusion and jealousy. Parents tried to deal with these problems by bringing the family together at weekends and holidays. The distress may not be obvious in the siblings during the period of the child's admission, but present afterwards. In one family, for example, an older brother presented

with severe learning problems that arose, apparently *de novo*, in a boy who had previously been doing very well academically.

The Effects of Death

A number of children have died, some before and some after transplant. The parents are always told in the assessment period what the risks of transplant are—at the moment one in 5 children die at the time of the transplant or within a few months of the operation. We feel that it is important that the parents know what the risks are. The decision to go ahead

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and have a transplant can be an agonizing one and is particularly so when the child looks well, as some of the children do even though they may have hepatic illness which is fatal in the long term. In the families where the child died during assessment or while waiting for a transplant, the issues included anger at the low donation rate and guilt at not having pushed for or agreed to a transplant earlier. This anger was sometimes directed towards the staff who were seen as not having been forthright enough. Some parents, however, expressed relief that their child had been spared the trauma of surgery.

In the families where death occurred after transplant, grieving was complicated by the knowledge that transplants are usually successful. These families often had considerable anger towards the nursing and the

medical staff for such complications as infection, or because they believed their child had been a "guinea pig." Often death occurred after a very stormy and drawn out postoperative course during which there was mounting anger about things going wrong. It was often difficult to maintain any contact with the family during this period because they became dismissive of any attempt to support them. The support of the extended family was very important, but for families who came from interstate or overseas, grieving was complicated by their isolation from family supports during the postoperative period and by their abrupt return home within days of the child's death. It was even difficult to maintain contact with those families who lived reasonably close to the hospital, although the social worker was able to offer some support with weekly phone calls. It was usual for the parents to return to see the pediatrician a few weeks after the child's death to talk about the causes of death, but perhaps because they had had such long painful experiences in the hospital, parents were very reluctant to return for more than this one follow up. There is an important place here for organizations not connected to the hospital to provide support during the grieving process.

Ethical Issues

Consent

Because in most cases it has been possible to take time to explain to the parents the problems involved in transplantation, getting properly informed consent for surgery has not been difficult. In children with biliary atresia who are only slowly becoming ill, the parents have the opportunity to meet other parents who have been through it. There are a number of photographs which parents have taken over the time of the surgery which we can use to show parents what they might expect. With very young

children obviously it is the parents' consent which is sought.

There have been major ethical issues relating to consent. One example of this was a parent with obvious severe psychiatric illness who refused consent. In the past this parent had withdrawn all treatment until the child had become seriously ill. The child had a liver disorder that necessitated she be continually kept under lights to rescue her bilirubin level. Any contact with the outside world was restricted for this four and a half year old. The court was asked to decide whether her mother's refusal to give consent was reasonable. As the result of the court case, the child was placed in the care of foster parents and had a transplant when she was five years and four months old. For the first time she was able to move away from the very restricted physical situation in which she had played and slept.

Non Compliance

One of the crucial questions during assessment was whether the family was going to comply with the medical regime. Compliance here meant issues like regularly attending outpatient clinics, taking essential medication continually, and providing consistent care at home. Ten of the families came from different or mixed cultural backgrounds, and with four of these families there was concern about the use of "native" medication or a lack of awareness about when the child needed medical attention. Three other children came from homes where there were problematic social conditions, and two of these children were taken into "care" through legal action in order to ensure that they could have the transplant. The third child died in hospital after the transplant. In her case, acceptance for transplant came after a lengthy assessment period where it was determined that a very supportive extended family was willing to support the child's mother who was unable to cope on her own. The

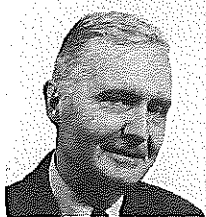
mother was separated from the child's father who was physically abusive, had had admissions, under police guard, to a local psychiatric unit, and had two other children as well as the child with liver disease.

The evaluation of whether or not a family were going to comply was often clear only after a lengthy assessment period which necessitated frequent outpatient visits; fortunately, the decision to put the child on the active waiting list could be delayed in some of these cases. The communal atmosphere of the liver transplant clinic which all children and families must attend serves a very important socialization process—informal networks of support and sharing are created as parents get to know one another while following their children's progress. A family who may have compliance issues learns, by seeing other families in the postoperative phases, what is important for their own child's well-being.

Summary

Liver transplantation in a child is a major stressor for both the family and the child. As integral members of a team, the social worker and psychiatrist function not as arbiters of whether or not a child should have a transplant, but rather as support for the child and family through the phases of transplantation—assessment, decision, transplant, and postoperative. Further work is particularly needed in two areas: 1) understanding the impact diagnosis has on the child and family and 2) exploring the emotional outcome of a more vigorous intervention at the time of diagnosis, especially in terms of resolving the grief over "losing" a "perfect child."

Editor's note: David Lonie is a psychiatrist and psychoanalyst who lives and practices in the wonderful world of Sydney, Australia. He is also a Regional Vice-President for WAIMH.



Stephen's Corner

Stephen Bennett

HOUSE RULES

I am trying to work my way across Canada, first the Maritimes, then Montreal and now Toronto, so as to counter my provincial American stance. An impression I get as I push my way across the continent is that the further west I go people are less inclined to tell me the complete story of their lives, which may be a formality and dignity that goes with the inner land. What emerged as a surprise to me during my visit to Toronto was a portrait of an institution as drawn from the people that spend their lives in it.

The Hospital for Sick Children in Toronto is spectacular. It transcends the usual Hyatt Hotel concept of inner atrium and surrounding rooms with its use glass walls all the way through, so with a soaring sense of space and airy openness you can see through to the outside, can see the sky. The feeling is not the isolation and confinement of the usual hospital, but instead that you are not in a hospital at all, and are still in touch with the outside. It is the kind of place that if you were sick, especially as a child, you wouldn't mind too much going there.

The central piece of the inner space is a pig in a tutu skirt with her barnyard friends watching her doing a pirouette on a tightrope. This figure, which can be moved back and forth at will of the hospital, appears on a post card you buy. I am accepting it as a central metaphor.

I started out the morning at the infant team meeting. Dr. Jean Wittenberg is the new chief of infant psychiatry team, having taken over

recently from Dr. Peter Sutton. Let me catch the genealogy. The lineage of infant psychiatry in Eastern Canada will turn up Klaus Minde somewhere. Minde started clinical work and research in the neonatal I.C.U. in the 1970's and in 1983 began an infant psychiatry service, but he left in 1986. Dr. Sutton took over the infant unit and pursued his research interest in parents who had lost an infant, a project which he had started as a resident. Also, he bridged the gap between in- and outpatient services with the infant team going back and forth between the two. Dr. Wittenberg became consultant to the N.I.C.U. when Minde left.

Present at the meeting were two part-time psychiatrists, George Awad, who had been there five years, and Ann Lazenby, who had been there for three years. All of them are psychiatrists and are part-time. Susan Goldberg, who acted as my guide for most of the day is a full time research psychologist.

Dr. Wittenberg tried to explain the reorganization in health care going on in Canada. As he described it, everyone wants to believe that Canada does better than other countries because as the Prime Minister put it, Canada was a kinder and gentler society. Their low-key sarcasm was a more dignified way of describing the situation than the yelling I would do about the bloody politicians and bureaucrats destroying health care. The real stuff came soon with some polite tension about work load. One psychiatrist stated gracefully that he had achieved his quota and didn't feel

like subsidizing a socialist system. If I understood the situation correctly, in the past, infant psychiatrists could bill for services like any other psychiatrist and would receive payment for anything they did. Everything is government-funded, but there are limits now on their billing with a cap, so the money is divided up, and infant psychiatry is given a certain allotment. Wittenberg described two themes in their research and clinical work: one is to assist the programs in the rest of the hospital and the other is to follow unique clinical and research interests, while still maintaining the hospital mission.

The hospital is a high-tech tertiary care organization, and those needs and themes tend to dominate. According to Wittenberg, there are no freewheeling ventures, and the staff must work within the goals of the hospital. Up until recently, people in infant psychiatry had done more or less their own thing. An example of this came from George Awad. He had just published a paper titled, "An Outpatient Treatment Program for Young Children with Pervasive Developmental Disorder." Any other organization would be proud of it. I'm always overjoyed when a member of our group does most anything. However, Awad's project was not on the approved list of topics. His research interest must be directed elsewhere and will now center on trauma.

I wondered then whether the hospital's demand for its faculty to stay within the mission would lead to dissension. My impression over the full day I spent there is that it would not. The reason was a curious good fortune. Among the hospital's interests were congenital illness, transplants, seriously ill newborns, and trauma. These issues provided a variety clinical and research themes for infant work, and the members of infant team responded with a fascination and enthusiasm. This was vividly so for Wittenberg and Goldberg, who were the teams members I got to know. I do

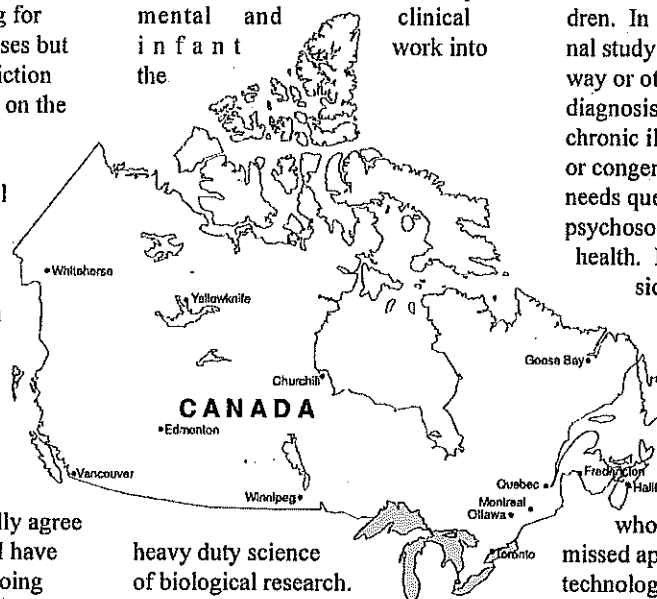
not think that anyone could stay long here unless they shared this excitement.

The overarching question brought out by Wittenberg was how does serious illness and hospitalization affect not only the development of the infant, but also the parent's response and care. Certainly, I am used to consultation/liaison work, but I had not experienced such a concentrated attention to major pediatric issues. There was an active searching for psychosomatic and trauma cases but guided by Wittenberg's conviction that the focus of care must be on the family. At the present time Wittenberg felt that infant psychiatry was seen as helpful by the hospital. When the team got through with informing me and down to business they concentrated on three themes: where they could fit in meaningfully into the hospital's clinical activities, picking up cases, and the question of just what kind of measures should they use. It sounded as if they would finally agree on something and stick to it. I have not had any great success in doing this.

I spent the next several hours with Susan Goldberg. She is open and friendly and really put herself out to show me around. Let me say that I try to deny the fact that it may not always be a blessing to busy and creative to people to have me poking and prodding about. Susan possesses the low-key comfort and wisdom of the old pro who has witnessed over the years all the confusions, struggles and personality battles that take place in any institution, but carries on with an appreciation for the weird, funniness of things. Her title at the hospital is research scientist, and she is the only psychologist in the psychiatry department who has a full-time salary to do research. The big catch is that she must find her own research

support from government and private sources.

There is in this hospital a separate research institution. Psychological research is really on the fringe of this institution. The major research thrust is molecular biology; in fact, from here came the discovery of the gene for cystic fibrosis and for Wilson's disease. It takes a sturdiness and stamina to persevere in pushing the wispy insights of developmental and clinical work into the



heavy duty science of biological research.

Susan Goldberg's education was Antioch College, then Tufts University. She received her Ph.D. from the University of Massachusetts. From 1975 to 1981 she taught at Brandeis. She got into infant work with Melvin Lewis at the Fels Institute in Yellow Springs, Ohio, where Antioch resides. I had not realized that Lewis had taken over there when Jerome Kagan left.

The whereabouts of gifted researchers is important to me because I feel that their presence uplifts clinical work. Let me digress here with my conviction that child development research is the basic science of clinical work. Access to these ideas in a more intimate way that reading the literature comes from real interchange which can happen at conferences, but

more important is to have such a person as part of a clinical unit. This is the role of a Susan Goldberg.

There was a two year interlude in Zambia after she left Fels. She studied children as part of the Human Development Research Unit. It is interesting that Klaus Minde was in Uganda at the same time and in some sort of vague way this how they eventually hooked up. In 1981, she came to the Hospital for Sick Children. In 1984 she began a longitudinal study which has continued in one way or other ever since. Once a diagnosis is made of a severe and chronic illness, such as cystic fibrosis or congenital heart disease, what next needs questioning is the impact of psychosocial issues on physical health. For example, 10 of the sickest children with cystic fibrosis were found not to differ in their physical status from other children who were doing well, but had in common families who had multiple problems and missed appointments. The fancy technology can keep these children alive, but it is their environment that decides whether they make it or not. In one sense, we can say that we all know this, and we do, but it is this research that nails it down.

Although responding to the needs of physically ill children is only one part of the work of infant mental health, it is a crucial part. There are major areas where we will be shut out or ignored unless we push our way in fortified with the conviction that we belong there. In the brave new world of managed care infant mental health care workers are less likely to be autonomous but must serve as consultants to primary physicians. A stint with Goldberg and Wittenberg would teach the diplomacy and teamwork necessary. In many clinical programs, consultation/ liaison work

often takes a back seat. One person is sent to try to deal with the harried pediatricians who only recognize a psychological problem if it hits them over the head, like blatant child abuse, for example. One survival thought is that to get paid we must prove our worth within the system of health care. A more beneficent view is that there are important areas where we can be of help if we make it clear we can do something.

Another area where these ideas apply is within the Early Intervention Programs in the United States. My impression—I hope that I am wrong—is that infant mental health has not

Another research issue is the relationship between attachment and emotional regulation. Attachment status at one year can predict the way emotion is regulated. Secure children can express emotion directly and do not have to work hard to get feelings across.

been very effective in becoming part of this system. Again, Susan Goldberg's data or the ideas of Arnold Sameroff as described in the next column are powerful means of first convincing ourselves, then other people, that we have a role.

Another research issue is the relationship between attachment and emotional regulation. Attachment status at one year can predict the way emotion is regulated. Secure children can express emotion directly and do not have to work hard to get feelings across. Their mode of expression is through their voice. Insecure children

have to work hard to signal emotions and to get attention—children classified avoidant use their body at high intensity and children classified resistant use their face. These ideas catch attachment in a dynamic sense and can be useful in psychotherapy. I have felt always that this aspect of attachment theory translates into something of real practical worth for the clinician.

One of Susan's current studies with Sharon Markovich is on children from Romania who have been raised in depriving institutions. There are over 100 who have been adopted by Canadian couples in Ontario. They have looked at attachment and have found that they all are indiscriminately friendly. There are no avoidant children, which makes sense in that this would not be a good survival tactic for an institution. Perhaps, however, in adult professional hospital life, the judicious use of avoidance would be a good survival strategy.

I was curious about the training offered at the Hospital for Sick Children and about opportunities for research. They had no rotating child psychiatry fellows, and in fact, the general residency program has decreased in size. There was a time when a diploma could be obtained from the University of Toronto in preparation for an academic position. Right now people are not banging on the door to do academic work and research. This was a surprise to me. My impression is that such interests were greater in Montreal and the opportunities wider.

Diane Benoit is the only full-time psychiatrist who is member of the infant team. She has been in Toronto for 3 years, coming via Queen's University in Kingston, Ontario, where she had been with Klaus Minde, and before that from Brown University in Providence, Rhode Island. I caught only elusive glimpses of her plunging down the long halls of the labs and offices adjacent to the main hospital, carrying her video

camera. Susan Goldberg described Diane's major interest as the evaluation and design of interventions for infants and toddlers who have feeding disorders. One specific group is children who were medically compromised and who had never learned to swallow. Her intervention is that she works directly with the child three days a week. She teaches the infants to eat by means of behavior modification techniques and then she trains the parents to do this. At present, she is evaluating the effectiveness of this intervention. What I sensed from far down the hall about her was a severity and intensity of responsibility to her population which left her little time for anything else. My own fantasy was of a figure from a Gothic novel so rarely seen down the long, dark corridors that one is unsure if she truly was there.

I ended up the day with Dr. Wittenberg in his private office down the street from the hospital where he enacts his other identity which is that of a psychoanalyst. Again, I marveled that intensely busy people agree to spend long hours with me. One reason was that he had a story to tell that caught his conviction about his role as spokesperson for sick children. Wittenberg is a trim man with rich grey hair and youthful face who presents an elegance of dress and graciousness of manner. My main sense of him was that he doesn't look like an infant psychiatrist, although I am not clear just what that would be. Certainly no jeans, open shirt, sandals or California image. In part it is that he looks like a psychoanalyst, of course, but even more so, an international banker. His powerful interest is in family-centered care. This is a consumer model which he feels is compatible both with good psychotherapy and with psychoanalysis. It stands in distinction from the strict medical model because it recognizes the authority of the parents. The history of the Hospital for Sick Children has caught his interest

because it illustrates the changing attitudes towards organized care for sick children.

Here is an example of an institution taking on a character and moral view. In the 1870's, a group of Protestant women took on the organization of care for the sick children of Toronto. The first model was that poor children were sick because of the neglect by their bad parents. Parents had no place in pediatric management. The medical model that had triumphed for most of this century allowed men to take over and was based on science curing all things. This did not happen. The attempt to provide care for chronically ill children showed that the parents had to be there, especially to help with all the machines necessary. The parents of these children felt that the doctors did not listen to them and so began to challenge the authoritarian medical stance.

Out of these energies and grievances was formed the Association for the Care of Children's Health. The focus was on health care rather than psychiatric issues. The theme developed was that the power of the family must be harnessed and that the people who used the services must have a major role. The message from the parents was, "You can't tell us what to do." Needless to say, many physicians would not be wild about that message.

Wittenberg got into these issues when as consultant for the Neonatal Intensive Care Unit (NICU) he became concerned about the parents. He was part of a committee that tried to enlist parental energies. The recommendation was that parents needed a high profile and presence in the hospital. A variety of ideas were tried and some were more successful than others. They tried to have parents present their perspective in all meetings, participate in teaching (including the medical students) to convey their need for parent-centered care, and to help other parents learn the ropes of the hospital. An attempt

was made to hire parents for this effort, but this did not come off. What I see in the city around me is little of this. In a city hospital there is a uniformed guard at the entrance to a pediatric service for the purpose of preventing kidnaping. In the construction of the hospital all the rooms have a bed for the parents. This was not entirely a success in that a single room for a child can be isolating.

Wittenberg described himself as always being interested in children. He had a year of pediatrics then a year

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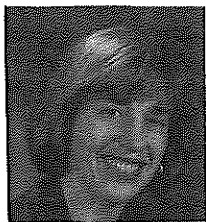
of child psychiatry in Scotland, where he was taken up with the ideas of Winnicott and Bowlby. He returned to Canada to private practice for awhile. After training in psychosomatic medicine, he finished with residency training in psychiatry and then obtained psychoanalytic training. Klaus Minde supervised him when he was a resident. When Minde left, he became the consultant to the NICU. Psychosomatic issues of infancy became a major interest for him. Wittenberg believes that so much of development starts with the physical, and he feels that many psychoanalysts don't have a clue about this.

At present, he is involved in a stunning array of clinical projects along this psychosomatic theme. He participates in the Failure To Thrive team and he is interested in children who have had a tracheotomy. He has tried to learn what the parents must cope with post operatively, especially

the child's trouble with eating. He works with eating disorders of a wide range, using an eclectic approach and works with many uncooperative parents. He works a lot with families using a short-term dynamic psychotherapy. He tries to help the child to work through maladaptive ways of handling troubles. Other groups are children who have been in the hospital a long time, such as children who are paralyzed or those who require ventilation therapy. Another group he has worked with is sighted children of blind parents. He has worked with the parents in his office and has helped them feed their infants. Also, he has gotten together a group of blind and sighted children.

My conclusion is that if Goldberg and Wittenberg and the others did not exist, the Hospital for Sick Children would have to invent them. For these three -- Wittenberg, Goldberg and the hospital -- the care of sick children becomes both character and morality.

Editor's Note: This is Stephen Bennett's penultimate column. He died August 14, 1995 while vacationing with his wife, Clare, in New Brunswick, Canada. His insightful column will be sorely missed.



President's Perspective

Joy D. Osofsky

The main issue on my mind and one in which we are all preoccupied is the upcoming 6th World Congress in Tampere, Finland on July 25-28, 1995. We are very pleased with the numbers of submissions to the meeting, as well as the enthusiasm being expressed both from colleagues in far distant regions such as Japan and South America, as well as those geographically closer, in the Baltic and Nordic regions. We are expecting to have a fine meeting both intellectually and personally and I look forward to seeing all of you there.

In the past 6 months, I have continued to travel, visiting and talking with WAIMH colleagues in many parts of the world. After our site visit in Finland, I chaired a workshop for WAIMH on Reality and Early Trauma: Developmental Pathways before the meeting of the International Psychoanalytic Association in San Francisco (at which Rex McGehee and Maria Cordeiro presented and WAIMH colleagues, Yvon Gauthier, Peter Fonagy, Serge Lebovici, Keigo Okonogi, Hisako Watanabe), participated in a symposium on Stress and Violence in Children and Youth in Lisbon, Portugal with representation from UNICEF and WHO (with WAIMH colleagues Maria Cordeiro, Jose Cordeiro, Salvador Celia, and Berry Brazelton), presented at a plenary session on Infant Mental Health with Keigo Okonogi at the 7th Scientific Meeting of the Pacific Rim College of Psychiatrists in Fukuoka, Japan, and conducted a workshop on Therapeutic

Interventions with Traumatized Infants to the Canadian Association of Psychoanalytic Child Therapists in Toronto, Canada (with WAIMH colleagues Elizabeth and Kas Tuters). I think that it may be of interest to the membership for me to briefly discuss some of the WAIMH developments in these different regions.

The workshop in San Francisco was very interesting and quite successful for WAIMH with an attendance of about 50 people. Two contrasting case studies, one a long term psychoanalytic case presented by Rex McGehee, and the other a short term eating disorders case by Maria Cordeiro, evoked a lively follow-up discussion around divergent theoretical, conceptual and treatment issues. Having workshops before the IPA meetings allows us to reach a different type of audience—more strongly psychoanalytic—as well as to educate others who may be less informed about the importance of therapeutic interventions in infancy.

In Portugal, Salvador Celia, WAIMH member from Brazil, and I visited the fine therapeutic intervention and research program that Maria Cordeiro is directing in Lisbon. The program began in 1983 with the support of the state to evaluate infants and mothers up to 3 years of age. Maria has recruited and is training a group of enthusiastic and talented clinicians and researchers. In her service, they see approximately 100 new infants and parents each year. The goal of the program is to diagnose, evaluate, and provide treatment

to mothers and infants with emotional and interactional problems, rather than mental retardation or disability. They see a variety of cases ranging from reactive problems including interactional dysfunction, social problems, neglect, affective problems, stimulation problems, and regulation difficulties. They also see infants with autism and pervasive developmental disorders which require longer term treatment. The three main components of their program involve dealing with individual problems within the family such as attachment issues that require individual or family work, providing community services for isolated families and immigrants, and serving as consultation liaison to pediatricians in the hospital for both inpatient and outpatient work. In addition to the fine clinical component, Maria's group is carrying out research on mental representations, particularly related to anorexia and depression, training general practitioners to do infant mental health work and evaluating their effectiveness, and studying 100 first consultations related to treatment outcomes. Maria Cordeiro and her group from Portugal will be presenting some of their work at the Finland meeting. In addition, Maria is working on the organization of a preconference workshop and symposium on the work being done with the DC: 0-3 Diagnostic Classification System in several countries in Europe. Salvador and I were very impressed with our visit to Maria's center. Afterwards we were treated to a wonderful Portuguese meal and fine hospitality by Maria and Jose Cordeiro.

In October, I traveled to Japan to visit Keigo Okonogi and his colleagues. This visit continued a wonderful tradition that we have established in WAIMH for the past decade of developing collaborative research and regional activities with Japanese friends. We had a very productive 3 hour meeting on the fine work that he and his colleagues have

been doing with the Japanese IFEEL Picture test which will be presented as a workshop in Finland. A special treat for me was to experience wonderful Japanese noodles (both udon and soba) and sushi for lunch during the meeting. For me, that is the height of terrific take-out food! This meeting was followed by a presentation and discussion of infant mental health issues as well as some of the work that I have done on young children who have been traumatized by violence. We had very interesting discussions about the similarities and differences for the children and families in Japan who were traumatized by the major earthquake. After several other meetings and an opportunity to experience the uniqueness of Japanese Kabuki Theater, I traveled to Fukuoka to participate with Keigo Okonogi in a plenary symposium on infant mental health. This symposium also had participants from China, Korea, and the Philippines who expressed much interest in learning more about WAIMH. Keigo and I will be exploring possibilities for expanding WAIMH activities to these other nearby countries. As most of you know, there has been much regional activity in Japan with two Regional Meetings of WAIMH in Tokyo in 1990 and 1994. In addition, several of the Executive Committee of WAIMH participated in an infant mental health symposium at the IACAPAP meeting in Kyoto in 1990.

I also traveled for WAIMH this Fall to Toronto, Canada at the invitation of the Canadian Association for Psychoanalytic Child Therapists and as guests of active WAIMH members, Elizabeth and Kas Tuters. Elizabeth is the Regional Vice President of WAIMH for Canada, and Kas organized the very successful meeting held in 1994 in Riga, Latvia. He continues to be active with colleagues in Latvia and other countries in the Baltic region. In addition to presenting a workshop on therapeutic interventions with trauma-

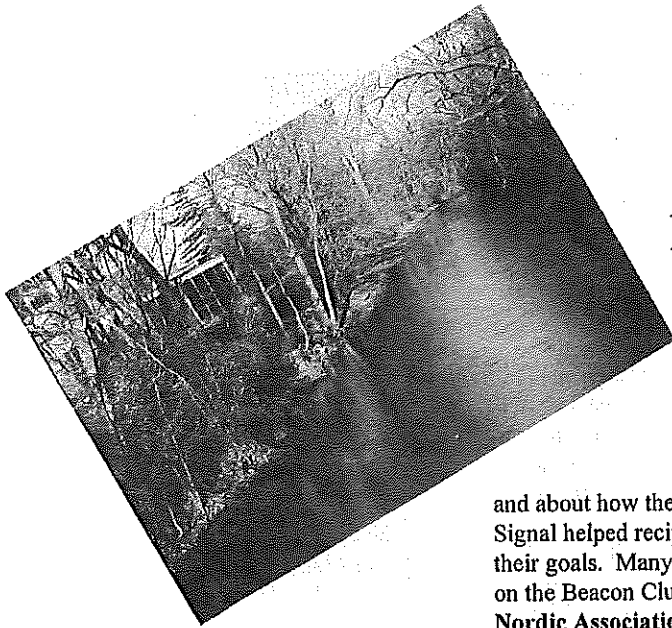
tized children, we had much discussion about revitalizing the Ontario Affiliate Group for WAIMH including an effort to broaden the activities beyond Toronto by developing better means of communication with other eastern and western provinces in Canada. I will be coordinating these efforts with our central WAIMH office. The group in Toronto is already publishing an infant mental health newsletter that may be the beginning of expanding communication efforts. We might even consider collecting through our WAIMH office in East Lansing, Michigan the different infant mental health newsletters of our various affiliates and once or twice a year sharing some of this information in *The Signal* to better inform the membership as a whole.

As we continue to plan for the 6th World Congress in Tampere, Finland in July, 1996, there is much WAIMH activity worldwide with growth of regional groups in many parts of the world. We look forward to continued excitement and efforts to develop and implement infant mental health programs. Please contact me by mail (Joy D. Osofsky, Department of Psychiatry, LSU Medical Center, 1542 Tulane Avenue, New Orleans, LA 70118), fax (504) 568-6246, or e-mail (JDOPS@UNO.EDU) if you have additional ideas about expanding our efforts or describing what infant mental health means in your part of the world. I will be delighted to include your comments and ideas in a subsequent President's column.



UPCOMING CONFERENCES

The annual conference for the Michigan Association for Infant Mental Health will be held April 28-30, 1996 in Ann Arbor, Michigan. Speakers include Alan Sroufe, Ph.D., Barry Zuckerman, M.D., Leslie Cunningham, M.D., Sam Meisels, Ed.D., Marva Davis, MSW, Ph.D. and Janice Fialka, MSW. For information call MAIMH's Central Office: 517-432-3793.



From the Red Cedar

Hiram E. Fitzgerald
Executive Director

Recordatus quondam super cenam, quod nihil cuiquam toto die praestitisset, memorabilem illam meritoque laudatam vocem edidit: 'Amici, diem perdidit.' [On reflecting at dinner that he had done nothing to help anybody all day, he uttered those memorable and praiseworthy words: 'Friends, I have lost a day.' (Suetonius, Titus, 8, 1; A.D. 39-81)]

The Beacon Club

Truth be told, many WAIMH members did not lose any days because they have helped to make significant advances in WAIMH's outreach project, referred to as the **Beacon Club**. During 1995, copies of the **Infant Mental Health Journal** and **The Signal** were sent to colleagues in Croatia (2), Hungary (1), Venezuela (1), Russia (2), Ukraine (1), Trinidad-Tobago (1), Yugoslavia (1), Czech Republic (1), Estonia (1), and Moldova (1), and an additional 10 copies were distributed by Clinical Psychology Publishing Corporation, Inc. through the New York international library distribution collaborative. A survey was mailed to all of the WAIMH sponsored agencies in order to learn about the programs of the recipients of Beacon Club fellowships

and about how the IMHJ and **The Signal** helped recipients to achieve their goals. Many thanks to everyone on the Beacon Club 95 Honor Roll: **Nordic Association for Infant Mental Health, Anni Bergman, Irene Chatoor, Robert N. Emde, Hiram E. Fitzgerald, Antoine Guedeney, Miguel Hoffmann, S. Lepine, Pickens Moore, Joy D. Osofsky, Hisako Watanabe, and Anne S. Williams.**

I hope that every Beacon Club 95 member will be able to sustain involvement in 1996 and that they are joined by as many WAIMH members as possible, especially all those who do not want to "lose a day."

Membership

During every year since its birth in 1992, WAIMH has reached its annual membership goal of 100 new members. WAIMH membership has reached 809, although the "official" membership toll for 1995 will not be available till we officially "close the books" for 1995. When renewal notices were sent out in October, every WAIMH member was asked to enroll a new member. Imagine the presence that WAIMH would have world-wide if it ended 1996 with 1600 members. The impact WAIMH could have on policies affecting infants and their families throughout the world would be significantly increased. Considering the conditions under which millions of infants and toddlers live in the world, enhancing

WAIMH's ability to influence world health policy is a reasonable goal for the association. So, here is yet another way to not lose a day—recruit a new member for WAIMH (and get them to Tampere for our World Congress!).

Tampere and WORLD CONGRESS VI

During the first week of January, the program committee will assemble in Tampere to make final decisions about the program in Tampere. The good news is that decision making will be difficult. With nearly 450 submissions, we can be certain that there will be many symposia, workshops, teach-ins, video presentations, and posters to complement the plenary sessions that have been planned. There also are important pre-congress sessions planned as well as opportunities for Affiliate Associations to network and to build stronger international collaborations. Work sessions on international communications technology also will be held and opportunities will be provided to assist WAIMH to develop stronger electronic access to training and educational materials. So there are many, many reasons to come to Tampere and to participate in the revolution we call, "infant mental health." *We hope that every WAIMH member will find some way to attend the world congress, especially since the next world congress will not take place until the year 2000!* In addition to learning about the cutting edge work being done in infant mental health throughout the world, World Congress VI will bring everyone to the charming and

provocative city of Tampere and will provide many occasions to embrace the wonderful culture and people of Finland. **Look for registration materials about the middle of January. For members from North America, opportunities to reserve pre or post congress trips to St. Petersburg, Russia will require reservations to be made by mid-February, so please read through the registration packet when it arrives. IF WE DO NOT RESERVE THE SHIPS FOR THE CRUISE TO ST. PETERSBURG IN FEBRUARY, WE MOST LIKELY WILL NOT BE**

ABLE TO OFFER THIS EXCITING OPPORTUNITY!!!

On a Personal Note

In conclusion, Melanie Smith and I would like to offer our very best wishes to all WAIMH members for a healthy, joyous, and successful new year. We hope that your efforts to improve the life circumstances for infants and toddlers throughout the world will bear fruit and that everywhere life will be just a little happier, just a little healthier, and just a little more promising for families with infants and young children.



Voices From the Heart

Are we really listening to the stories of mothers of special needs children?

by John Hornstein

The following article is reprinted from "Everyday's Child," newsletter of the Maine Association for Infant Mental Health.

My sister called—who is my best friend, and told me she is uncomfortable at our house, she's uncomfortable with me, she doesn't think I love Laura, she's uncomfortable that we don't serve alcohol with our dinner, she thinks I have pity for our son Dustin, not love—I feel just awful inside—I feel like I did when my father and Lindsey died. I know this is an opportunity to look at myself and . . . I know that the relationship will probably be different after this and I think that is probably good. But I feel really crummy right now . . . Then she told me not to tell anybody. (Kathy, 11/26/1991)

Kathy's daughter Laura has cerebral palsy. Like many, if not most, mothers of children with special needs she is isolated from community, friends and even relatives. In dealing with the professionals who treat her child she often feels diminished and powerless. She fights a constant battle with these professionals and with the larger community on behalf of her daughter. She is a nurse who has given up her career in attempting to meet these demands. She often feels confused about who she is and what the future may bring. She struggles to be heard, but often ends up silencing herself.

Kathy's need to be heard, her lack of power, her confusion about self, and her self-silencing are shared by many mothers of children with special needs. They are also feminist issues. It seems to me if we are to adequately understand these women and the development of their children we must design research and intervention

strategies that not only provide a clear picture of their experience but that also provide a voice so that their concerns can be heard. In their struggles with power and isolation these women may teach us more than what it is to be a parent of a child with special needs. Their stories are stories of personal change and resilience as well as of pain and frustration.

The article is based upon the stories of the mothers of the Parents in Partnership project. Over the course of three years nine mothers in collaboration with staff of the Muskie Institute at the University of Southern Maine developed training and materials for professionals who work with families of young children with special needs.

Most of the research in this field, however, has been done on, rather than with, these families. The preponderance of research on mother-child interaction has shown that mothers of infants with handicapping

conditions tend to be more directive and engage in a higher level of activity in interactions with their infants than mothers of non-handicapped infants. This tendency has been demonstrated in less turn-taking in early vocal interactions (Berger & Cunningham, 1983; Mahoney, 1988), in lack of responsivity in replay interactions (Hanzlik & Stevenson, 1986), and in redirection and interruption in joint attention to toy exploration (Landrey & Chapiesky, 1989). According to these studies there is a tendency for these mothers to use a set of strategies that take control of the interaction and of the child's activity. Even when the researchers find that the directiveness may be related to greater rather than lesser sensitivity to the children's behavior (Tannock, 1990) the mothers are subjects of and not participants in the studies.

Videotaped mother child interactions are rated according to elaborate coding schemes in which both maternal and infant behaviors are analyzed. Mothers are subjects in the studies, and although they are typically asked to answer a few questions about child-rearing and to fill out questionnaires which, for example, assess levels of depression, they are never formally asked about the interactions themselves. A very rich source of data, it seems to me, is excluded from these studies, further perpetuating the position of powerlessness and silence in these mothers.

An exception to the overall neglect of maternal perspectives in research on parent-child interaction with handicapped children is the use of the Ainsworth strange situation with mothers and their young children with cerebral palsy by Marvin and Pianta (1992). They apply the notion of "internal working models" as developed by Bowlby, Main, and Bretherton to the examination of these interactions. Through diagnostic and adult attachment interviews with the mothers they describe maternal working models and show how these

models relate to responses to the strange situation. They speculate that unresolved previous loss on the part of mothers can have a strong effect on the security of the mother child relationship in these dyads with a resultant negative effect on self-reliance in the children. This focus on the context of other significant relationships and the mother's perception of those relationships is promising but hardly typical of research in this field.

In application, the field of early intervention has made great strides in becoming more sensitive to family issues. Over the last several years the field has experienced a revolution from child-centered approaches to those which see the family as the focus of service delivery (Dunst, Trivette and Deal, 1988). Along with new strategies to empower parents and mobilize social support, assisting parents in personal adaptation is now seen as a primary means through which the child's development can be supported.

The predominant model applied to such psychosocial work with parents of young children with handicapping conditions is in assisting them with managing their grief (Left & Walizer, 1992; Seligman, 1991; Oehler, 1981; Canino & Reeve, 1980). This grief is seen as that for the loss of the "ideal" child, and treatment involves strategies to assist parents in managing stages of shock, anger, bargaining, depression and acceptance (Seligman, 1991). Despite the change in focus of the field as well as significant emphasis on assisting with the grief process many parents continue to express concern with a lack of understanding on the part of professionals (Left & Walizer, 1992). Not surprisingly, difficulty in adapting to the stresses of parenting a handicapped or chronically ill young child continues to be a major source of concern for these parents (Hanson & Hanline, 1990).

What current approaches in practice fail to recognize, I think, are the fundamental issues of self that are confronted by these parents. They are not allowed to be the people they used to be, or want to be. They are not only grieving for the loss of an ideal child, but also for the loss of their own past and idealized future selves. The context in which this change occurs is often one in which they feel isolated and powerless. Neighbors and helping professionals often build barriers between themselves and these mothers. Even sisters, husbands and fathers tend to move away. In some cases the movements may be unconscious or unintended, but the effect on the parent is greater isolation. There are exceptions; husbands who are present, mothers who become even more available. But the largest number of interactions and relationships that these mothers describe are ones which serve to distance rather than bring close.

Traditional research approaches as well as related direct service applications have failed to adequately reflect the experience of mothers of children with special needs. Rather than provide significant insights into those experiences they have tended to portray these parents in a stereotypic and objectified manner. They have failed to supply a satisfactory portrayal of their self perspective, and, in the process have maintained a power imbalance in which the professional/researcher supplies the knowledge and controls the context.

In order to arrive at a more satisfactory treatment of the experience of these parents elements of a feminist epistemological framework as described by Cook & Fonow (1990) could be used. In such an approach gender and gender asymmetry are acknowledged in the experience of these women in society. Particularly in relation to power in relationships, interactions with professionals, husbands and fathers an imbalance of authority and status may contribute to

the ability of these parents to establish their own sense of self-efficacy as well as advocate for their children.

Neilsen's (1990) argument that less powerful members of a society have a more complete perspective of social phenomena is particularly relevant in the case of these families. As they experience and articulate their isolated perspectives they are also bombarded with advice and judgments from professionals, neighbors and friends who portray the prevailing cultural norms and expectations. The contrasts are dramatic as is seen in Kathy's example:

... I remember someone saying to me once, 'Because of Laura, I think your family has to look at things a little more carefully. You might also want to look at some of the specific issues, like co-dependency.' Those type of comments make me angry. Another person, a dear friend of mine, said to me one time, 'I think these are issues that you will need to bring to your therapist, you know, your enablement, your co-dependency, your rigid style ...' It makes me feel exposed, with no privacy. It makes me mad.

Kathy both understands and experiences the judgment of society around her, but she also articulates her feelings about that oppression. . . . Consciousness raising, then, serves as a methodological tool. Indeed, that is what the Parents in Partnership project was all about. The expressed purpose was to raise the consciousness of both professionals and parents.

Another of Cook and Fonow's points is that of challenging the norm of objectivity. This point, I think, is critical. It is precisely the self perspective of the mothers that is missing from the study in this field. It is also what makes the Parents in Partnership material so rich. Many of the stories recorded in *From the Heart* were generated in the meetings of the mothers. The recorded dialogue between the mothers is constantly empathic, reflective and emotional.

The focus on the single subject is often merged with that of a group interaction. These interactions serve to enhance the individual response, and the individual response reflects a contribution from the group. The stories are biased by common experience as well as by feelings of oppression. My involvement and acceptance in the group was based, in large part, upon my willingness to share my own personal experience with disabilities and alienation. It is, in my opinion, impossible to access the perceptions of these women by means of traditional social science experimental modes. Their experience is one of distance and alienation. Traditional research methods only serve to increase these factors.

This leads to a third concern discussed by Cook and Fonow—the use of research as a means to affect social change “... research must be designed to provide a vision of the future as well as a structural picture of the present (p. 80). This is both the start and the endpoint of this research. . . .

Instead, then, of looking at the stories of these mothers from an objective professional distance we must adopt an approach that brings ourselves into the reading, that truly listens to the voices of these mothers.

The women of the Parents in Partnership project tell compelling tales of their experiences of parenting a child with special needs in the face of an unsupportive and isolating society. The fact that a mother is told that it is o.k. for her son to have two left feet (his other foot was amputated after a bout with cancer) is important. How she is told, how she reacts, and how she tells the story are all important elements in understanding her experience.

The reading for self is at the core of this inquiry. Do these women truly feel that they have lost themselves?

And how do they view themselves now? The reading for the self allows us to hear those selves: “It brings us into relationship with that person, in part by ensuring that the sound of her voice enters our psyche and in part by discovering how she speaks for herself before we speak of her. Thus we include her voice in our description of her, attempt to know her on her own terms, discover the resonances in our own psyche, respond to what she is saying emotionally as well as intellectually.” (Brown, L. & Gilligan, C. 1992, p. 272.

Reading for isolation and connectedness is a way to attend to the context of relationships that so strongly affect how these mothers see themselves—“how they experience themselves in the relational landscape



It is, in my opinion, impossible to access the perceptions of these women by means of traditional social science experimental modes. Their experience is one of distance and alienation.

of human life” (Brown & Gilligan, p. 29). The inner circle of these mother's social support system is that of extended family, friends and neighbors. Current research in early intervention maintains that this informal system of support is far more likely to be utilized than professional services (Dunst, C., Trivett, C. & Deal, A., 1988). Their descriptions of their interactions with this informal system should provide insights into the nature of that support. Is it described with a voice of isolation and alienation? Or, is a sense of connectedness and support described?

The following narrative is from Susan, a member of the Parents in Partnership parent team:

It affects the relationship I have with neighbors. It's easier for them not to get to know me or like me because we are so different, because of Jeremy. He is visibly very different.

It pours over into everything. The hard part as a parent is that we are the ones, every time, who just have to keep picking ourselves up and putting on that strong face and going ahead. It matters though; it hurts. Sometimes you think you'll get used to it, but you don't ever get used to it, and it just keeps on happening, over and over, and it's hard.

What do you do when you live in a world with other people, and other people don't know and understand? A lot of time I think it's because of the way they have been raised in this culture. Rather than just thinking, 'Well, I'm going to go over and get to know this kid and family,' they are really uncomfortable. They don't know what to say. They don't know what to do. It puts a lot of responsibility on us as the parents. My whole personality has changed as a result of this.

Susan's story is one of anger and frustration. She describes how it is, how she and her family are stigmatized and isolated. She tells us that it doesn't go away. She describes the constant burden that she feels. The neighbors are representative of the culture, a culture that won't accept Jeremy and her. As the oppressed she also tells us about the perspective of the oppressors, "they are really

uncomfortable." But she doesn't accept that perspective. She doesn't like this fight, she describes it as a battle, but she seems to have accepted the responsibility despite the costs.

In reading for self I hear Susan's alienation. It's easy, as she says, for people not to get to know her. "We are so different." It's as if she and Jeremy are stigmatized as a unit. She steps outside herself to talk about what "you" do when you live in a world of other people who don't understand. But at the end she tells us that her whole personality has changed. She doesn't go on to tell us in what way it has changed her. Perhaps she has implied that she has had to learn to become a fighter or an extrovert. Or perhaps she has chosen not to let us know how she has truly changed.

In reading for isolation I hear Susan not accepting it. Her neighbors find it easy not to get to know her. She feels the responsibility not to make it hard. She is fighting isolation, but it is unrelenting. Again, "We are so different." It's a statement. She has accepted the difference, but not the isolation.

There is clearly connectedness with her son. There is no question that they are in this battle together. But there is also a connectedness with other parents who are in similar

situations. Her audience at this point in the dialogue is a group of mothers who have similar feelings. She finds resonance for this message in the group. "... we are the ones, every time, who just have to keep picking ourselves up and putting on that strong face and going ahead." She is rallying the forces and in a way, she is acknowledging their strength together.

In reading this and many of the other stories these parents tell I find incredible strength. Yes, they have been changed by their experiences in an oppressive society that can't accept their difference. They didn't choose this difference. It happened to them. And they tell us of that pain. Perhaps some of that pain is the loss of the "ideal" child. Some of it, I suspect, is also the loss of self and of dreams. But there is such a will in these women to take on the society, the neighbors who ignore, the professionals who blunder, and the relatives who disappear. These stories are stories of personal change and resilience as well as of pain and frustration.

"What do you do when you live in a world with other people, and other people don't know and understand?"

You teach them how to listen.

Editor's Note: John Hornstein is a doctoral candidate at Harvard University's College of Education, an Instructor at the University of New Hampshire and a board member of the Maine Association for Infant Mental Health.

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