Family Work and Families with Children with Disabilities

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ABSTRACT

As the deinstutionalization process sees more children with disabilities placed at home with their families, families are experiencing burdens and stress in their continuing care lifestyle.

This paper presents a generic model of family assessment derived from the structural approach to family therapy. It also draws upon the accumulated knowledge base concerning effects on family of a child with a disability which has developed over the past twenty years. Skill and knowledge are then combined in the presentation of a case example which demonstrates family assessment in a family with a child with a disability. The technique of family sculpting as it was used during the assessment is presented.

This paper supports the development and assertive provision of family work services to families who can be identified as potential high stress families simply by virtue of having a child with a disability at home.

The past two decades has witnessed a profound shift in the type of services provided for families of children with disabilities. This shift, known best as the deinstitutionalization movement (Nirje 1970, Wolfensberger 1972) needs no introduction to we health and welfare professionals who have experienced it personally in so many aspects of our work. But while we would support the principle of deinstutionalization on the grounds of an ethical choice, we are also poignantly aware of some of the problems which have occurred in the community as the concept was implemented.

One of these problems concerns the new burdens and stresses experienced by families who form the support system of those who previously were institutionalized. In providing support and maintenance to the persons with disabilities community tenure, the family also take on a 'continuing care lifestyle'. A continuing care lifestyle does not have to be restrictive, constrained and self-sacrificing. It can in fact be very positive, providing rewards and experiences other families may never know. This is more often the case where the necessary support services are provided and functioning smoothly (Joyce, Singer and Isralowitz 1983, Cavanagh and Ashman 1985).

However, for various reasons including the current marked world economic constraints, and the fact that deinstitutionalization is occurring in the real world and not in an idealogue's clinic, the support services are often not in place and families are increasingly bearing the shifting burden.

According to the system's theory view of the family as an open living system, families display a quality known as negentropy (von Bertalanffy 1968). That is, families differentiate and organise around information or events which they recognise as significant. Families in fact can adapt in internal organisational terms in a manner which is dysfunctional in the long term. And long term is the time period we are considering in addressing the continuing care lifestyle. To make this point more clearly, when families take on the care of a child with a disability, they adapt to the stress and burden by reorganising. In reorganising, costs as well as savings are made, and this can lead to family members feeling hurt, neglected and bitter in the long term.

The purpose of this paper is to consider the systemic effects on families as they cope with a continuing care lifestyle which is necessitated by the presence of a child with a disability. A schema for assessment of family functioning will be presented. This schema is known as the structural approach and is but one of many schools of family therapy which has developed from systems theory. This theoretical presentation will form the basis of the subsequent application of the theory to practice as we consider some findings from the literature and a case history. The technique of family sculpting which has been very useful in working with families of children with disabilities, will be discussed.

However, before proceeding, it is necessary to point out that family therapy is not a panacea for the problems of families with a child with a disability. These families require support services such as respite care, early intervention facilities, financial assistance and various physical therapies, if they are to have a fair chance of successfully engaging in a continuing care lifestyle. Family therapy is about caring for people and the relationships in the family to maximise health and well being. It is but one aspect of the total range of services required.

STRUCTURAL FAMILY THERAPY AND FAMILY ASSESSMENT

Family therapy based on systems therapy, is predicted on the concept that the individual is primarily an acting and reacting member of systems. Thinking in terms of systems necessitates a conceptual leap from the notion of the individual acting upon his or her environment as a unilateral force. While this is not a new concept in itself it is a new concept in the field of mental health which had traditionally focussed on the individual as a separate entity in both diagnosis and treatment. Structural family therapy developed in the second half of this century as one of many responses to the growing idea of the interrelatedness of the individual and the environment.

Succintly stated, structural family therapy believes that the individual's experience of reality depends upon the feedback processes between the individual and his or her circumstances. "The psychological structure of the individual is viewwed as interdependent with the person's social structure and that social structure is treated as the medium through which the individual functions and expresses him/herself" (Aponte 1981)

The individual is viewed as self-in-context. This concept goes beyond understandings of the personal and historical determinants of self to include an understanding of the individual as he or she actualizes in situ. The individual is seen as an acting and reacting part of transactional patterns in a mutual and circular reinforcing pattern. Certain parts of the individual are emphasised and reinforced in different contexts and as patterns evolve, exclusion of other parts of the individual occurs. Inner processes, that is, how the individual understands self, other and experiences, primarily result from context.

Assessment regarding functioning and dysfunctioning in families is essentially a matter of examining whether the family's structure enhances the enactment of its functions as it moves through the family life cycle, giving due regard to social cultural contexts. In this present context, 'structure' is assessed in terms of boundaries, alignment, power and organisation as operationalized in transactional patterens which occur as the family carries out its functions. The term 'function' refers to purposive activities necessitated by being a part of a family, such as parental discipline or mutual spouse support. Over time and experience, certain structures will tend to dominate in relativity of occurrence, and others will tend to be subordinate. For example, a dominant structure might be seen in a family where the mother usually disciplines the children, and the subordinate structure is seen when the father takes on this role. Boundaries, alignment, power and level or organisation are structural dimensions the therapist will assess as he or she witnesses or hears about a family's transactions.

Boundaries, by their nature, both include and exclude. A boundary can then be assessed in terms of who is in and who is out of a particular transaction. Boundaries also define role because transactions occur as a result of functions being operationalised. The function of boundaries "is to protect the differentiation of the system" (Minuchin 1974, p83) such that it is sufficiently free from the intrusion of others to carry out its functions. Minuchin (1974, p54) recognises the nature of boundaries as a continium from rigid, through clear, to diffuse. A rigid boundary describes a relationship characterised by the disengagement of its actors. There is little effective communication in such a relationship and the behaviour of one has little impact on the other. A diffuse boundary describes an enmeshed relationship characterised by an increase in communication and concern, each to each. Although such relationship types are functional in different life stages and in different contexts extremes of such patterns over time can result in symptomatic behaviour and inhibit the natural processes of growth and maturity. A disengaged family may not be able to respond when response is indicated, and an enmeshed family may not be able to respond when response is indicated, and an enmeshed family may respond too quickly

and intensely thus inhibiting the development of autonomy and self expression. Thus the nature of the boundary is a dimension of family functioning which may require therapeutic intervention.

In working with a family with boundary problems, the therapist is focussed on the permeability or rigidity of boundaries within the family, and between the family and its context. Individual or subsystem differentiation is dependent on the relative ease with which information as energy, can pass the boundaries. The therapist may also need to focus on violation of boundaries by a family member who is inappropriately carrying out functions which are the socially or culturally prescribed domain of another subsystem.

Within boundaries, family members engage in relationships which are characterised by certain patterns of actor arrangement. Aponte describes such alignments as the "joining or opposition of one member of a system to another in carrying out an operation" (Aponte 1976, P434), where 'operation' refers to the functions actualized in specific activities. The dimension of alignment includes concepts of coalition, when two individuals join to act against another, and alliance, where two people join because of a shared interest.

In structural family therapy, the therapist considers the alignment dimension in terms of such arrangements as stable coalitions, triangulation, and detouring coalitions (Minuchin 1978). A stable coalition occurs when two family members join against another in such a way that it becomes a dominant and inflexible transactional pattern regardless of the issue or functional requirements. A detouring coalition is a stable coalition whose purpose is to diffuse the tension of a situation by focussing on another person as the cause of the problem. Triangulation describes a situation in which two individuals seek to align with the same third person who becomes caught in issues of loyalty and may seek to escape by developing symptomatic behaviour. Within boundaries and against a background of alignments, the concept of power refers to whose will prevail when discord is encountered. Power is a relative concept rather than an individual attribute. One may have power in a particular context, or in exercising a particular function, but may have less power in affecting the outcome in a different context.

In considering family dysfunction the therapist assesses the presence of absence of the power necessary to execute functions. If a family member has a function to execute, he or she must have the power to exercise it. If a parent is required to discipline, she must be free of issues of fear or favour to execute it appropriately. If a child is required to develop autonomy, he must have the necessary power to make age appropriate decisions and engage in age appropriate activities. A further dimension of structural problems in families is level or organisation. "The ability of a family to function will depend on the degree to which the family structure is well defined, elaborated, flexible and cohesive" (Aponte 1981, p315). Underorganisation is a problem seen often in socially disadvantaged families who, as a result of stressful circumstances of living, are not able to develop the necessary organisational structures to cope with the unique demands of each function giving due regard to consideration of context and individual need.

In structural family therapy, dysfunction is assessed in terms of the dimension/s (boundary, alignment, power, level or organisation) which appears to be mostly contributing to the symptomatic behaviour and the inability to function.

The litmus test of dysfunction is whether the family structure works without any individual developing symptoms, and whether normal developmental growth and maturity can occur. The structural approach to family therapy sees the family as a natural context for growth and healing and the unimpaired ability for this to occur is assessed in terms of the dimensions outlined.

In the process of therapy, the therapist assesses the problem in terms of data gathered as he or she joins the family system. The therapist hypothesises according to the dimensions outlined and sets goals for change relating to a more functional structure. Intervention ensues with the therapist responding to feedback from the client family. The therapist is essentially a conductor who has the expertise the authority to effect change in a manner conducive to the family's preferences.

FAMILIES WITH CHILDREN WITH DISABILITIES

The birth of a child with a disability or the discovery that a child in the family is disabled constitutes a crisis for the family. The family is likely to experience an acute grief reaction resulting from the loss of the anticipated perfect child (Solnit and Stark 1961, Mandelbaum 1967, Parks 1977, Emde and Brown 1978)

They are subsequently presented with a complex array of problems and tasks not experienced by families without a child with a disability. Such families have to deal with problems of obtaining a complete diagnosis, frequent medical and therapeutic interventions, dealing with a range of professionals, extra costs incurred by the necessity for aids and transport to treatment centres, decisions about future pregnancies, lack of appropriate child care, decisions about where to live, home modifications, job opportunities forgone because of difficulties in moving the settled family, revised expectations about mother returning to the work place and ignorance in the community and the resultant isolating stigma.

During the course of the family's life and development, it will also experience transitional and developmental crises which are occasioned by the discrepancy between the actual and expected performance of the child with a disability. (Wilker, Wasow and Hatfield 1981, Wikler 1981).

The family copes with these extra demands by re-organising structurally in the best way they know how. As it is used here, the term 'know' can be an intuitive or experience-based type of knowing rather than simply a cognitive process. This is, each family member delves deep into their wealth of personal experience, knowledge, values, intuition and creativity to adapt to the situation. Over time, a new structure will emerge, a structure which will be relatively homeostatic until again disturbed by a transitional or developmental crisis. One thing which can be assumed about the family structure is that it is the best the family has to offer at this point and in its present context. People do not deliberately jeopardise family happiness — they do their best given the total range of constraints and possibilities which they experience and know.

The purpose of therapeutic intervention in the family's process of structuring and restructuring is to help the family to discover if and where costs and compromises are being experienced and to creatively discover more functional structural possibilities.

An overview of the literature on effects on families of a child with a disability is suggestive of where family stress is often experienced. This provides useful information to the family therapist who must be mindful of longer term and developmental trends. However, simplistic conclusions regarding effects on families should be used only as indicators because there are a variety of influences and factors which must be taken into account.

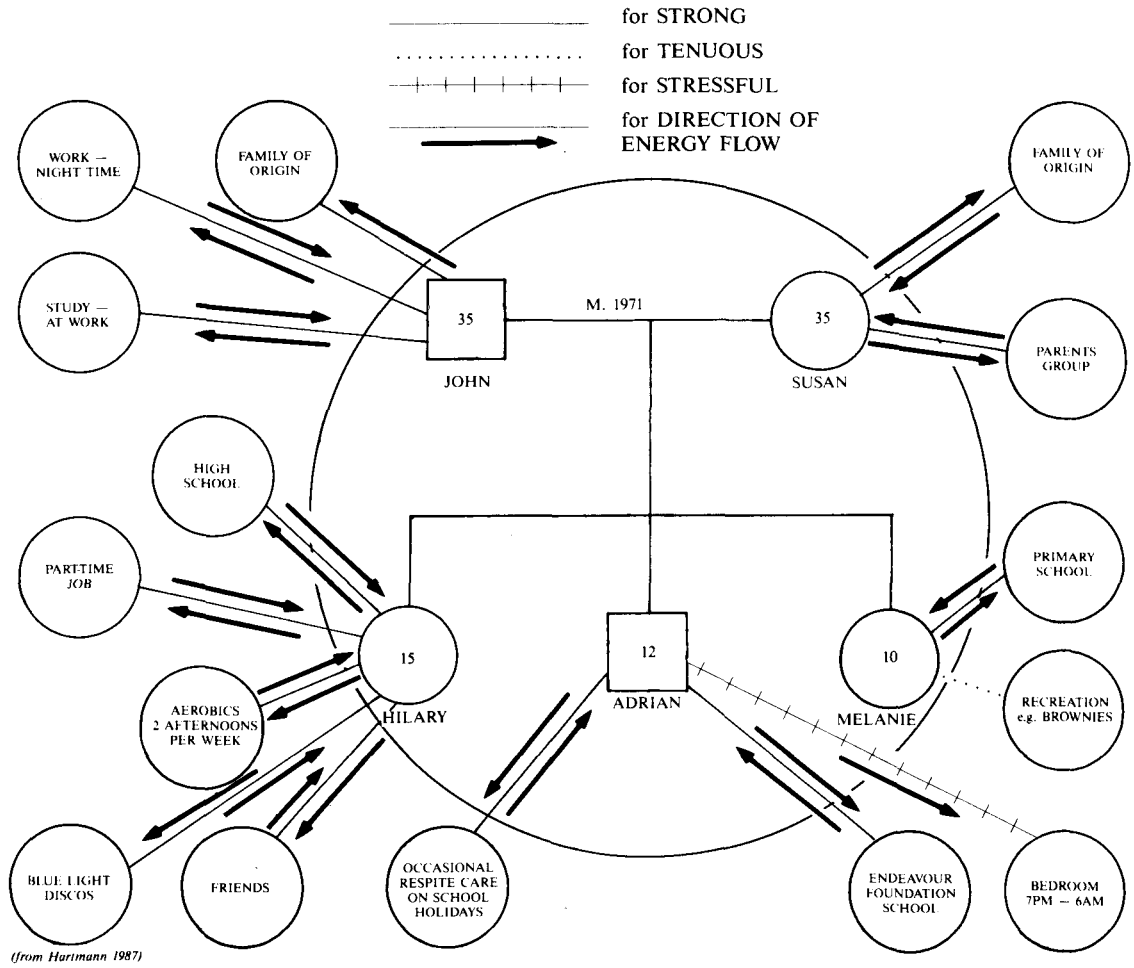
There is evidence in the literature that parents with a child with a disability experience greater marital stress than those without a child with a disability (Gath 1977, Friedrich and Friedrich 1981) and that those whose marriage relationship was sound before the birth of the child with a disability were more likely to remain together than those whose relationship was poor. Overall, the rate of diverce does not differ significantly between families with a child with a disability and those without (Davis and Mackay 1973, Shufeit and Wurster 1975).

Siblings of children with disabilities have also been extensively studied. The findings suggest that siblings generally adopt their parents' attitude toward the child with a disability (Klein 1972), such that it is not possible to find consistent responses of siblings across families. It has been found that older siblings can provide caring functions for the child with a disability but that they may become rejecting if required to adopt parent duties (Telford and Sawrey 1977). Gath (1974) found that deviant behaviour and educational failure was experienced by older female siblings who may have carried a larger share of the burden of care which resulted in neglect of her own needs. There is also some support for the idea that siblings of children with disabilities may be neglected as much of the parents' time and energy is directed to the child with a disability (Poznanski 1973, Tew and Laurence 1973, Gath 1973).

In terms of the family's interaction in its social environment, families with a child with a disability can be more isolated, being less able to participate in recreational and sporting activities (Margalit and Raviv 1983), although Waisbren (1980) found that younger children with disabilities posed less restrictions than older children with disabilities.

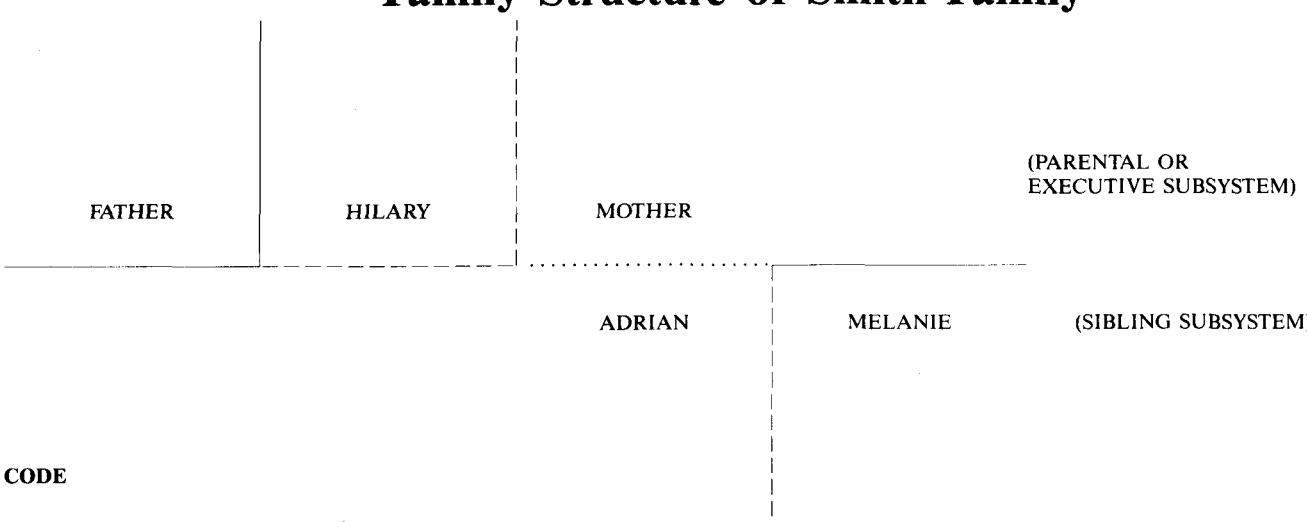
The family worker who is involved in the family with a child with a disability should be aware of generic dimensions of family functioning as well as the more specific experiences of families with children with disabilities. The worker must also take a view of the family which takes into consideration its developmental stage and its ecology or context.

FIGURE 1
Genogram and Eco-Map of the Smith Family



(from Hartmann 1987)

FIGURE 2
Family Structure of Smith Family



CODE

_ _ _ _ _ _ _ _ _ Clear Boundary

. . . . . Diffuse Boundary

_____ Rigid Boundary

(from Minuchin 1974)

CASE EXAMPLE OF FAMILY ASSESSMENT*

The following is a case example of a structural analysis of family functioning in a family with a child with a disability. The technique of family sculpting is used in the assessment process and in subsequent intervention. A genogram/eco-map of the family is presented in Figure 1.

The Smith family live in their own home in a small coastal town. The father, John, works at a night time desk job where he spends much of his time studying his five year correspondence course. He is imbued with a sense of wanting to better himself, to be somebody. He sleeps during the day, only spending afternoons with the family before going off to work again in the evening. Susan spends much of her time working with the Parents Group lobbying for much needed support services. Hilary is the oldest child. At age fifteen, she goes to school and leads an active social life which is encouraged by Susan. Adrian is a twelve year old boy with a severe physical and intellectual disability. He is mostly wheelchair dependent and has little independence in self care skills. He does not speak but can make sounds. Melanie is ten years old, but one has the impression she is much younger, just as Hilary seems much older than her age. Melanie is quiet, and likes to play with Adrian or by herself in solitary games.

I became involved in the family because they were having marriage problems. One of the techniques used during therapy was family sculpting, a technique developed by Duhl (1973) and used extensively by Peggy Papp (1977).

Family sculpting consists of each family member taking turns to arrange the other members in postures and positions which are physcial and spatial representations of their relationships, interactions and feelings. The sculptor is supported by the therapist who observes, clarifies and interprets the sculpture as it is generated. Papp (1973 p202) has said of family sculpting:

"The essence of one's experience in the family is condensed and projected into a visual picture. The picture is literally worth a thousand words, revealing aspects of the family's inner life that have remained hidden. Vague impressions and confused feelings on the periphery of awareness are given form through physcial spatial expression."

The family sculpting exercise can also extend to have the sculptor begin to consider new possibilities of actor arrangement by trying to construct a tableau of ideal arrangements.

In the family sculpting session with the Smith family, there was considerable agreement between family members as each took turns to be the sculptor. A compilation of the main features is as follows:

John was placed on one side of the room looking across to Susan on the other side. Susan was placed holding up Adrian in a standing position in front of her. She had to use both hands to do this as Adrian would otherwise fall. Malanie was placed beside, but a little away from mother raching up to her pleading for some time and attention. Susan was looking back at her feeling simultaneously annoyed by the extra demands on her while her hands were full, and guilty that she never had time to respond to Malanie. Hilary was placed half way between her father and mother, reaching out to her father who had become increasingly estranged.

In terms of the dimensions of family functioning outlined earlier, Susan's relationship with John is characterised by a rigid boundary, that is, they are disengaged, communicating rarely and ineffectively. Susan's relationship with Adrian is marked by a diffuse boundary, that is, they are enmeshed in terms of the concern Susan shows for Adrian. The history of Adrian's disability including grand mal epileptic fits and two strokes has resulted in Susan being finely tuned or resonant to Adrian's behaviour. The extent of his handicap requires quick response and an ever aware parent. One could hypothesise that this enmeshment is linked structurally with the disengagement of the parents, although one should not continue on to say that one caused the other. Looking for causes leads to blaming and is not focussed on freeing up the system. It is suffice to be aware of what is happening here and now, and to consider future possibilities.
The disengagement of the parents can also be linked with Hilary's violation of the parental subsystem boundary which has become diffuse and easily crossed. Hilary is placed in the parental subsystem trying to hold on to the disengaging father. Alternatively, Melanie is still within the sibling subsystem but experiencing considerable hurt as her needs are often neglected. She can see her father leaving and she is frightened. With no one to meet her needs, she is turning inwards and becoming isolated. The one person she still has contact with is Adrian and this contact is mainly expressed physically by cuddling and romping around the lounge together. However, as mother pointed out, "That will have to stop soon — they're both getting too big for that sort of thing". The structural analysis would be represented diagramatically as in Figure 2.

In terms of the literature finding reported previously, there is evidence in this family of some of the common experiences of families with children with disabilities. In particular these are neglect of the emotional needs of one sibling, that is, Melanie; extra pressure on the oldest female sibling to fulfil parental roles; and extra stress on the parental relationship which is related to the extra tasks involved in caring for a child with a disability. It is interesting that Susan, Hilary and Adrian are all engaged in positive and age appropriate social interactions while John's are few, highly structured and constrained, and Melanie has persistently not engaged socially out of the family despite considerable efforts by Susan to encourage this.

Based on this assessment of family functioning and on the knowledge base of effects on families of a child with a disability, the family therapist would have some messages for this family about ways in which they could pay attention to themselves and about some potential hazards in their developmental course. The therapist might suggest that the parents take time to look after their own relationship even though they may not feel motivated given their current distance from each other. The therapist may also suggest that Hilary be relieved of her functions in the parental subsystem and may encourage the family to consider what needs to change for Hilary to be able to let go of that position. With respect to Melanie, the therapist would want to make sure that her messages about her unhappiness and her reluctance to grow up are interpreted to the parents in a way that they might respond positively rather than react negatively. The therapist may also like to talk to Susan about expanding her idea of self from one which is restricted to the roles of mother, daughter and wife. John may also benefit from being encouraged to discover some positive aspects of himself and to discover that the grass is green on his side of the fence too.

Family therapy offers a rich range of useful intervention techniques such as reframing, metaphor, task setting and paradoxical injunctions which could be used by the family worker.

This case example of the assessment of family dynamics in a family with a child with a disability demonstrates the application of the structural family therapy approach. It also demonstrates the usefulness of the technique of family sculpting in deriving the assessment. Therapy with the family can now proceed from a systemic assessment of individual experiences and interactions.

CONCLUSION

The purpose of this paper has been to report on the appropriateness and usefulness of a family therapy approach in facilitating the healthy adjustment of families with a child with a disability.

It is considered usual now for families to care for their child with a disability at home where this is possible. However, the presence of a child with a disability can produce extra stresses in the family and family relationships can become dysfunctional as they adapt structurally to accommodate to extra stresses.

This paper has outlined a schema for the structural assessment of family functioning. The application of this generic assessment schema was then demonstrated in its use with a family with a child with a disability. The assessment schema and the technique of family sculpting were also used in conjunction with a knowlede base concerning effects on the family of a child with a disability, which was derived from the literature in this field.

Now more than ever before, there is need for the development of family work skills and knowledge to help families cope with their extra burdens. Family work services should be assertively provided to families who can be identified as carrying extra burdens as a matter of promoting healthy adaptation, if not preventing dysfunction.

**Names and identifying factors have been changed. The family have given permission for the case to be presented.*

REFERENCES

Aponte H.J. (1976), Underorganisation in the Poor Family, in Guerin, P.J., *Family Therapy Theory and Practice,* Gardner, New York.

Aponte, H.J., Van Duesen, J.M. (1981), Structural Family Therapy, in Gurman, A.S., Kniskern, D.P., *Handbook of Family Therapy,* Brunner/Mazel, New York.

Cavanagh, J., Ashman, A.F. (1985), Stress in Families With Handicapped Children, *Australian and New Zealand Journal of Developmental Disabilities, 11* (3), 151-156.

Davis, M., MacKay, D. (1973), Mentally Subnormal Children and Their Families, *The Lancet,* October 27.

Duhl, F.J., Kantor, D., Duh, B.S. (1973), Learning, Space and Action in Family Therapy: A Primer of Sculpture, in Bloch, D.A., *Techniques of Family Psychotherapy,* Grune and Stratton, N.Y.

Emde, R., Brown, C. (1978), Adaptation to the birth of a Down's Syndrome Infant: Grieving and Maternal Attachment, *American Academy of Child Psychiatry, 17,* 299-323.

Friedrich, W.N., Friedrich, W.L., (1981), Psychosocial Assets of Parents of Handicapped and Non-handicapped Children, *American Journal of Mental Deficiency, 85* (5), 551-553.

Gath, A. (1977), The Impact of an Abnormal Child upon the Parents, *British Journal of Psychiatry, 130,* 405-410.

Gath, A. (1974), Sibling Reactions to a Mental Handicap: A Comparison of Brothers and Sisters of Mongol Children, *Journal of Childhood Psychology and Psychiatry and Allied Disciplines, 15,* 187-189.

Gath, A. (1973), The School Age Sibling of Mongol Children, *British Journal of Psychiatry, 123,* 161-167.

Hartman, A. (1978), Diagrammatic Assessment of Family Relationships, *Social Casework* 5 (9), 465-476.

Joyce, K., Singer, M., Isralowitz, R. (1983), Impact of Respite Care of Parents' Perceptions of Quality of Life, *Mental Retardation, 21,* 153-156.

Klein, S.D. (1972), Brother to Sister: Sister to Brother, *The Exceptional Parent, 2,* 10-15.

Mandelbaum, A. (1967), The Group Process in Helping Parents of Retarded Children, *Children, 14,* 227-232.

Margalit, M., Raviv, A. (1983, Mothers' Perceptions of Family Climate in Families with a Retarded Child, *Exceptional Child, 30,* 163-169.

Minuchin, S. (1974), *Families and Family Therapy,* Harvard University Press, Cambridge.

Minuchin, S., Roseman, B., Baker, L. (1978), *Psychosomatic Families,* Harvard University Press, Cambridge.

Nirje, B. (1970, The Normalization Principle: Implications and Comments, *Journal of Mental Subnormality, 16,* 62-70.

Papp, P. (1977), *Family Therapy: Full Length Case Studies,* Gardner Press, New York.

Papp, P., Silverstein, O., Carter, E. (1973), Family Sculpting in Preventative Work with "Well Families", *Family Process, 12* (2), 197-212.

Parks, R.M. (1977), Parental Reactions to the Birth of a Handicapped Child, *Health and Social Work, 2,* 52-68.

Poznanski, E. (1973), Emotional Issues in Raising Handicapped Children, *Rehabilitation Literature, 34,* 322-326.

Shufeit, L.J., Wurster, S.R. (1975), Frequency of Divorce Among Parents of Handicapped Children, *Resources in Education,* U.S. Department of Health, Education and Welfare, National Institute of Education, ED113 909.

Solnit, A., Stark, M. (1961), Mourning and the Birth of a Defective Child, *Psychoanalytic Studies of the Child, 16,* 523-536.

Telford, C., Sawrey, J. (1977), *The Exceptional Individual,* Prentice-Hall, New Jersey.

Tew, B., Baurence, K.M. (1973), Mothers, Brothers, and Sisters of Patients with Spina Bifida, *Developmental Medicine and Child Neurology, 15,* 69-76.

Von Bertalanffy, L. (1968), *General Systems Theory: Foundations, Development, Application,* Brazellier, New York.

Waisbren, S. (1980), Parents' Reactions After the Birth of a Developmentally Disabled Child, *American Journal of Mental Deficiency, 84,* 345-351.

Wikler, L. (1981), Chronic Stresses of Families of Mentally Retarded Children, *Family Relations, 30* (2), 281-288.

Wikler, L., Wasow, M., Hatfield, E. (1981), Chronic Sorrow Revisited: Parent vs. Professional Depicting of the Adjustment of Parents of Mentally Retarded Children *American Journal of Orthopsychiatry,* 51 (1), 63.

Wolfensberger, W. (1972), *The Principle of Normalization in Human Services,* National Institute of Mental Retardation, Toronto.