A PARENTS ASSOCIATION FOR DEVELOPMENTALLY HANDICAPPED PRESCHOOL CHILDREN: A CASE STUDY OF A SOCIAL WORKER'S CONTRIBUTION TO A SELF-HELP GROUP

by

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

INTRODUCTION

> The absence of empirical data on self-help groups is well known and is reflected in the book. Clearly it is a fertile but complex field for future research.
>
> --from a review of The Strength in Us: Self-Help Groups in the Modern World (in Social Work, Sept. 1976, Vol. 21, No. 5), p. 410.

> The best way to test all these conclusions is to experiment with community workers and with a variety of structures for community associations and other groups, monitoring each situation carefully.
>
> --from Alan C. Twelvetrees, Community Associations and Centers: A Comparative Study, p. 148.

America has been frequently characterized as a nation of joiners. Both the historian and the sociologist have taken note of the variety of associations, clubs, and special-interest groups which attract men, women, and children from every class and ethnic group in our society. It is not only the sheer number of associations nor the incredible variety of such associations which fascinate the student of history or sociology. What is considered remarkable as well as perplexing is the fact that these associations are based on 'voluntary action.' Voluntary action, typically, has the following features: (a) non-coercive participation, (b) non-remunerative participation, (c)

organized activity performed collectively, (d) participation is often temporary, (e) often consists of purposive action oriented toward effecting or controlling social change.[1]

The involvement of a professional with a 'self-help group'--a subcategory of voluntary associations--is what this study is all about. Twelvetrees defines, in typically British terseness, self-help groups as "a group which concentrates on its own needs rather than on those of other groups."[2] A more elaborate definition is given by Alfred I. Katz and Eugene I. Bender:

> Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers also have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem, and bringing about desired social and/or personal change.[3]

In these two definitions as well as the definition of self-help groups by Thomasina Borkman[4] no mention is made of any outside assistance or, more specifically, assistance given by a professional. In his recent comparative study of community associations in England, Twelvetrees observes that community associations can either evolve from the grass-roots or can be mandated by legal or

statutory requirements. None of the associations, which Twelvetrees studied, were formed with the assistance of a professional staff member. He suggests that ". . . a third formative model, which would appear to have the merits both of the 'grass roots' and the 'outside intervention' model, might be where an 'enabler' got to know felt needs in an area and encouraged people to form an association to meet those needs."[5] In other words, 'very much yet very little' is known about the development and growth of self-help groups--i.e., how do they in fact get started? What prompts people to participate? What emerges when an enabler, representing an organization, assumes an active role in the formation, maintenance and goal direction of such a group?

This study is a detailed description and analysis of an action research social service project--namely, the creation of a hospital-based auxiliary association (Parents Association For Retarded and Developmentally Disabled Preschool).* The Parents Association represents the 'coming

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*In September 1976, the parents decided to drop the phrase "retarded and developmentally disabled." They preferred the wording "developmentally handicapped" because retarded has too many negative connotations.

together' of a professional and parents/consumers at the beginning of the creation of a self-help group. This coming together of professional and parents is, by definition, a contradiction in terms--if not a contradiction then certainly a paradox: since self-help groups are usually not formed with the assistance of professional person(s). And in the field of mental retardation and developmental disabilities, which has a long and rich history of self-help groups (parent associations)--both within the United States and in European and Asian countries--professional assistance usually came after a Parents Association had successfully obtained a service for retarded individuals.* There is no documentation in the literature of professionals and parents collaborating at the formative stage, that is, when the parents make the decision to organize into an association.[6,7]

The description and analysis of the Parents Association is to cover the association's formative stage--from January to June 1976. However, reference will be made to

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*Up until the 1960's human service professionals (psychiatrists, psychologists, pediatricians, social workers, etc.), generally, were either disinterested in the programmatic needs of the retarded or reflexively recommended institutional placement for the retarded individual.

certain critical incidents (e.g., losing the Board of Education Special Education Teacher and publicity by a major T.V. Station) that occurred after June 1976).

Although this was an applied research project, it is not an experimental study: there were no control or contrast groups, participants were selectively rather than randomly chosen. The project was basically a case-study: a detailed description of program efforts (amounts and kinds of program activities), program effectiveness (to what extent are the objectives achieved), and program efficiency (expenditures of manpower, time, money, physical equipment).[8] By describing the process of the program; by highlighting specific, particularly organizational, variables; and by specifying the theoretical frames of reference which underpin and guide the project; this report should give the reader a sense of what happened, how it happened, and why it happened, so that the reader may traverse the same or similar territory but, hopefully, with much less risk. As Polansky and Weber state, "For nothing ever goes exactly according to plan, and the discovery that certain possible interventions cannot actually be carried out may be as useful as knowing which other techniques were

able to be offered but had no discernible effects."[9]

In this project this writer assumed two primary roles: practitioner and researcher (observer). However, all of his actions were dictated by his role as practitioner. At no time did he, in his work with either the parents or with professional staff or administrative members of the hospital or with persons outside of the hospital (e.g., Board of Education personnel), remain passive or neutral as a researcher might have conducted himself: unless remaining passive or unobtrusive was dictated by programmatic considerations.

Throughout this report this writer shall refer to himself as either staff advisor or researcher. Parents Association For Developmentally Handicapped Pre-school Children will be referred to as simply, Parents Association.

Notes

1. David Horton Smith, Richard D. Reddy, and Burt R. Baldwin, eds., Voluntary Action Research: 1972 (Toronto: O.C. Heath and Company, 1972), p. 127.

2. Alan C. Twelvetrees, Community Associations and Centres: A Comparative Study (Oxford: Pergamon Press, 1976), p. 139.

3. Alfred H. Katz and Eugene I. Bender, The Strength in Us: Self-Help Group in the Modern World (New York: New View Points, 1976), p. 9.

4. "A Self-help group is defined here as a human service-oriented voluntary association made up of persons who share a common problem and who band together to resolve the problem through their mutual efforts." Thomasina Borkman, "Experiential Knowledge: A New Concept for the Analysis of Self-Help Groups," Social Service Review 50 (September 1976): 445.

5. Twelvetrees, p. 81.

6. Rosemary F. Dybwad, "The Voluntary Association on the International Scene," Mental Retardation and Developmental Disabilities: An Annual Review VI, ed. Joseph Wortis (New York: Brunner/Mazel, 1974), pp. 273-289.

7. Wolf Wolfensberger, The Third Stage in the Evolution of Voluntary Associations for the Mentally Retarded (Toronto: National Institute on Mental Retardation, 1973), pp. 3-10.

8. Tony Tripodi, Philip Fellin, and Irwin Epstein, Social Program Evaluation (Michigan: F. E. Peacock Publishers, Inc., 1971), pp. 43-50.

9. Norman A. Plansky, ed., Social Work Research (Chicago: The University of Chicago Press, 1975), p. 192.

CHAPTER I

CURRENT TRENDS AND CONCEPTS

> Resort to life in institutions is less and less necessary and will probably disappear in another 25 to 50 years.
>
> Every individual, no matter how severely impaired, is capable of learning so long as life endures and the person is in any way responsive to the environment.
>
> --from Mental Retardation: Century of Decision (President's Committee on Mental Retardation, March 1976), p. 20.

The three au curant key phrases in the field of mental retardation and developmental disabilities are institutionalization, normalization, and continuum of care.* The former is a negative code word--a word that conjures up images of vegetating individuals, non-activity, and brutal living conditions. In contrast to this gruesome picture, normalization and continuum of

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*Developmental disabilities is a broader concept than retardation. It is a term which acknowledges that more often than not a retarded individual may have other disabilities such as cerebral palsy, hydrocephalus, seizures, etc.

care are concepts which project a much more favorable image--active individuals, purposeful activity, family-type living conditions, and perhaps even a caring and loving staff.

What do these words mean? Encapsulated in words, particularly words which are employed by planners and policy makers, are basic value premises, empirical or apriori knowledge and community power arrangements.

Courage is now required for any Social Worker to defend institutionalization as a treatment choice for the retarded. Those professionals who are anti-institutions can cite the horrors committed in the name of "treatment" as well as the studies which document the benefits for a child who can be sustained in his own home.[1] And if the child's parents cannot assume their parental responsibilities, an ersatz family, not an institution, is proposed: adoption, foster care, group homes, hostels. Not only is an institution considered inhumane compared to (say) group homes, but it is also viewed as too costly. For example, Willowbrook, an institution for the retarded in New York City, which once sheltered as many as 5,000 residents, is being phased out as a result of a court

suit brought by parents, the State Association for Retarded Children, joined by the Legal Aid Society and the Civil Rights Division of the United States Department of Justice.

At a recent court hearing, expert testimony stressed two themes: (a) the need for home-like or nearly home-like settings (foster homes, group homes) for the retarded so that each person can receive individual care as well as love and attention; and (b) estimated cost at Willowbrook is about $15,000 a year for each patient as compared to $5,400 per patient in a group home in Connecticut or $3,360 per year for foster care in New York State.[2]

Although many institutions for the retarded are large and may even accommodate populations larger than 2,000, 'size' is not a component inherent in a more precise and accurate definition of the word. A facility that houses 100 or 50 or 7 can be referred to as an institution. Size, then, though a critical and significant factor, is not a defining characteristic.

Three possible ways of defining something are connotative, operational, or denotative. For purposes of this analysis, we need only to be concerned with connotative or dictionary definitions. When a word is defined

connotatively, it is defined by using another word or set of words; one concept is employed to explain another concept.

One word can belong to different linguistic worlds. For the sociologist, 'institution' is an 'interrelated system of social roles and norms organized about the satisfaction of an important social function.' How does the policy maker in the field of mental retardation define institution? In his The Economics of Mental Retardation, Ronald W. Conley equates institutions with 'sheltered living.' Conley states:

> Sheltered living may range from complete and total care in an institution to periodic visits by a social worker. In between these extremes are a number of possibilities, offering varying degrees of protection and supervision, including group homes or boarding houses.[3]

In a similar vein, Theodorson and Theodorson define institution (in a policy sense) as follows:

> A place of confinement or partial confinement where persons of a specialized type live, following a formalized life routine under the control and direction of a bureaucratic staff, and having limited contact with the rest of society.[4]

An institution, then, is in business to offer protection, services, and supervision for the retarded.

A word, however, has a 'common sense' definition or

a 'man-in-the-street' definition. What has happened is that all the horrendous characteristics which have been associated with 'large' institutions for the retarded have become the 'defining characteristics' of the word institution. A group home is in fact an institution to the extent that it represents a degree of confinement, formalized routine, and is under the direction of a bureaucratic staff. It becomes institutional, however, when it is discovered that the group home is a place where its residents perhaps do little more than wait for death.

What has been discredited on both humanitarian terms (i.e., the goodness test) and in fiscal terms (i.e., the efficiency test) is not the concept of sheltered living, only that quality individual care is almost impossible in a facility which houses thousands of residents.

Defining a concept as precisely as possible is not just a linguistic exercise. The basic assumption of this applied research project is that a retarded and/or developmentally disabled preschool child--even a profoundly/severely retarded child*--can probably do better (in terms

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*Mildly retarded--IQ 50-69; Moderately--IQ 36-49; Severely--IQ 20-35; Profoundly--IQ 0-19.

of self-help skills, motor development, acquisition of language) in his home if and only if s/he is exposed to specialized programs within his own community. In some instances, however, either the nature of the child's disability is so severe or the family's coping capacity is so limited or strained, that placement of the child into an institution is the only viable alternative. The Parents Association recognized that they had a strong selling point when they argued that a preschool program was needed because without such a program some parents might decide that their only choice is to place their child in an "institution." The fact that institutions have been discredited by policy makers (as the last treatment choice!) within the mental health field (New York City Department of Mental Health and Mental Retardation), has given parents as consumers a very effective argument for the need for a variety of programs within their local communities.

'Normalization' and 'Continuum of Care' represent two concepts which are a direct outgrowth of the 'discrediting of institutions' as the primary living arrangement for retarded individuals. What is normalization? It is a policy which states that the retarded individual

should be given the same opportunities during his life-cycle that are provided for the average citizen. A theoretical definition is proferred by Bengt Nirge:

> . . . The normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are close as possible to the norms and patterns of the main stream of society.[5]

An operational definition is suggested by Gunnar Dybad:

> Thus human management service in mental retardation must be predicated on the availability to the parent of the same array of diagnostic and informational, therapeutic and supportive services that a forward looking community must make available to all its infants and young children.[6]

The concept of normalization rests on a basic assumption which is implicit in the definition--namely, that how an individual gets labelled (i.e., "retardation," "handicapped," etc.) is not based on objective findings. We can say, philosophically speaking, that retardation is not a ding an sich--a thing in itself--but involves how society reacts to its less able citizens. If a person is defined as handicapped because he deviates in some way from what he himself or others believe to be normal or appropriate,[7] then a policy of normalization attempts to make the retarded appear as normal as possible. If normal or average children (say) go to camp; or if normal children

join the boy scouts or girl scouts; or if normal pre-schoolers are enrolled in nursery schools; then the more the retarded individual has the same opportunity to go to camp, join a scout group, or to be enrolled in a preschool program--the better the chance that s/he will not be perceived as a handicapped person. And the more others react to a person as a developing human being rather than (say) as an eternal child or an object of pity, more normal or appropriate behavior will be elicited from the retarded individual.

In other words, normalization represents a value stance (viz., that giving the retarded individual an array of opportunities as is given the average citizen is more humane than segregating the retarded within institutions) as well as a policy based on empirical knowledge--that behavior is often a response to how one is perceived by others. Normalization is an attempt to change how our society has traditionally perceived the retarded (e.g., object of scorn, object of pity, eternal child, etc.).[8] When the Parents Association began to negotiate for a pre-school program, they wanted a program not only to be under the auspices of the local district school board but to

have the program located within a school building without architectural barriers); they were operating under the policy of normalization--viz., they wanted their children to be perceived as students rather than patients because not only others but they as parents would begin to think of their children as more normal and less handicapped*--or a child with a handicap rather than a handicapped child.

The policy of 'continuum of care' is inextricably linked to the concept of normalization. Both normalization and continuum of care can be considered as two sides of the same coin. Whereas normalization encourages the same provision of services and opportunities to the retarded as given to the normal population, continuum of care is a policy which states that services and programs must cover a wide spectrum of goals. Program planners who have endorsed continuum of care as a viable policy have drawn charts and hypothetical flow charts (Table 1) which reflect the variety of services a retarded individual may require at

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*The chairperson of the Parents Association has used the fact that if normal children need nursery school as preparation for elementary school then certainly children with special problems need such preparation as one of her major arguments for a preschool program for developmentally handicapped children. A normalization argument par excellence!

TABLE 1

FLOW CHART: CONTINUUM OF CARE SERVICE FOR THE RETARDED

LIFE STAGE	Diagnosis Counseling Medical Care	PHYSICAL AND MENTAL HEALTH	SHELTER NURTURE PROTECTION	INTELLECTUAL DEVELOPMENT	SOCIAL DEVELOPMENT	RECREATION	WORK-ECONOMIC SECURITY
INFANT		Testing, Screening Home Nursing	Residential Nursery Child Welfare Services				
TODDLER		Physical Therapy	Foster Care	Nursery School			
CHILD				Special classes - Educable Special classes - Trainable			
YOUTH		Pental Care Psychotherapy			Social Clubs	Day Camps	
YOUNG ADULT			Hostel				Selective - Job Placement Sheltered Employment
ADULT				Evening School			
OLDER ADULT			Boarding Homes				

different life-cycle stages.[9]

For example: A retarded individual, like any other individual, requires medical services throughout his life. But he may need a scouting program during preadolescence. Homemaker service is needed whenever (say) his mother is admitted to a hospital. In other words, some services are continuous, from infancy to old age (e.g., medical care); some are of limited duration (e.g., scouting); and some are required from time to time (e.g., homemaker services). Continuum of care is a policy which is predicated on the assumption that whatever service is required, be it scouting or diagnostic evaluation, it must be accessible to the retarded and his family. It also accepts an implicit premise of the normalization policy: that the retarded do not belong in institutions. That services must be provided for the retarded so that institutions would be the choice of last recourse (or, to use child welfare language, 'the least detrimental alternative').

Preschool Programs

The International League of Societies for the Mentally Handicapped in 1968 and the General Assembly of the United Nations in 1972 had adopted a bill of rights for the retarded. One such right is "the right to education and

training appropriate to developmental status."[10] As early as 1963 and 1966 articles appeared in professional journals which argued for the provision of preschool programs for retarded children.[11,12] In 1976, sixteen years later, there are programs which seek to enroll "babies."[13] The rationale for enrolling children as early as eighteen months for purposes of educational stimulation is based on the research of Dr. Burton L. White of the Harvard Graduate School of Education: who states that any child over three years of age who is six months or more behind in language and problem-solving skills is destined to have difficulties throughout his school career.[14] What is interesting to note is that the rationale is for all children, not certain groups of children (e.g., children from minority groups, or children with handicaps).

Head Start, which was established in 1965 under the auspices of the Office of Economic Opportunity, is a compensatory program for preschool children from impoverished parents most generally Black and Puerto Rican families). Whereas some programs for preschool children have stressed cognitive development, headstart has traditionally stressed social-emotional development.[15] The rationale for day care,

however, is not only to provide the preschool child with educational and social stimulation but to allow the parents, particularly the mothers, to get off public assistance and to become gainfully employed. Whatever the rationale--be it cognitive development, compensatory education, or getting mothers off public assistance (AFDC), --preschool programs (for 3 to 5 year olds) are established programs under either public or private or voluntary auspices.

Within the context of continuum of care, preschool programs for retarded and developmentally disabled children is a required educational service. The National Association of State Directors of Special Education, employed the Delphi method (the projections of the future based on personal expectations of knowledgeable individuals) on a variety of issues which pertain to special education. There was a strong consensus that by 1983 twenty five states would have incorporated programs for young handicapped children in day care centers.[16] In New York State, however, school districts may provide (but are not legally mandated) classes for handicapped preschool children. However, under the new Education for All Handicapped

Children Act the federal government--for the first time--helps pay states for added education costs for children from 3 to 18 by September 1978 and 3 to 21 by September 1980.[17] Preschool programs for handicapped children have finally received legal recognition.*

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*The fact that New York State does not legally mandate preschool programs for handicapped children (ages 3 to 5) is the reason why the Parents Association lost the special education teacher from the New York City Board of Education--at least that was the official written explanation given to the parents by the Board of Education. Personal letter from Chancellor Irving Anker to the staff advisor: "The inadequate dollar allotment we received necessitated our reaching the unhappy decision to transfer the funds previously used for preschool children to our Early Education section where the Board of Education has the legal responsibility to provide adequate services for handicapped children." (dated December 9, 1976)

Notes

1. Philip Lichtenberg and Dolores G. Norton, Cognitive and Mental Development in the First Five Years of Life: A Review of Recent Research (Maryland: National Institute of Mental Health, 1973), pp. 87-91.

2. Frank J. Prial, "The Willowbrook Trial: Still A Sore Issue," New York Times, 20 September 1975, Sec. 2.

3. Ronald W. Conley, The Economics of Mental Retardation (Baltimore: The Johns Hopkins University Press, 1973), p. 353.

4. George A. Theodorson and Achilles G. Theodorson, A Modern Dictionary of Sociology (New York: Thomas Y. Crowell Company, 1969), p. 207.

5. Benght Nirge, "The Normalization Principle and Its Human Management Implications," Changing Patterns In Residential Services For the Mentally Retarded, eds. Robert B. Kugel and Wolf Wolfensberger (Washington: President's Committee on Mental Retardation, 1969), p. 181.

6. Gunnar Dybwad, "Action Implications, U.S.A. Today," Changing Patterns in Residential Services For the Mentally Retarded, eds. Robert B. Kugel and Wolf Wolfensberger (Washington: President's Committee on Mental Retardation, 1969), p. 404.

7. Brian H. Kirman, The Mentally Handicapped Child (London: Thomas Nelson and Sons Ltd., 1973), p. 13.

8. Wolf Wolfensberger, Normalization (Toronto: National Institute on Mental Retardation, 1972), pp. 16-24.

9. George M. Beal and Janet S. Payer, Mental Retardation: A Guide to Community Action (Iowa: Iowa's Comprehensive Plan to Combat Mental Retardation, 1965), p. 12.

10. President's Committee on Mental Retardation, Mental Retardation: Century of Decision (Washington, D.C.: U.S. Government Printing Office, 1976), p. 18.

11. Gunnar Dybwad, The Mentally Handicapped Child Under Five (Lecture at the Town Hall, Oxford, September 1966; reprint ed., Texas: National Association For Retarded Citizens, 1974), 2-16.

12. Gunnar Dybwad and Edward La Crosse, Early Childhood Education is Essential to Handicapped Children (Journal of Nursery Education, January 1963; reprint ed., Texas: National Association For Retarded Citizens, 1974), pp. 1-12.

13. "School District, Seeking 'No Fail,' to Enroll Babies," New York Times, 23 July 1975.

14. Ibid.

15. For a good succinct overview of the history and analysis of preschool programs (nursery, day care, headstart, Piaget vs. Skinner, etc.) see "Child Welfare: Preschool Programs," Encyclopedia of Social Work (2d ed.; New York: National Association of Social Workers, 1971), pp. 128-139.

16. William V. Schipper and Leonard A. Kenowitz, Special Education Futures: A Forecast of Events Affecting the Education of Exceptional Children: 1975-2000 (Washington, D.C.: U.S. Office of Education, Department of Health, Education, and Welfare, 1975), p. 11.

17. The National Information Center For the Handicapped, Closer Look (Washington, D.C.: Office of Education, Bureau of Education for the Handicapped, U.S. Department of Health, Education, and Welfare, Summer-Fall 1976), p. 1.

CHAPTER II

THEORETICAL FRAMES OF REFERENCE

This section will attempt to explicate the various theories and models which underpin a voluntary auxiliary association as a (i) vehicle to obtain a specialized pre-school program and (ii) a structure of professional-parent collaboration. One of the primary reasons why the evaluation of social service programs has been so problematic (or difficult!) is that planners fail to specify why they expect the program to succeed (i.e., to produce a specific outcome).[1] Carol Weiss observes that knowing the theoretical foundation of the program (particularly the 'causal connections') helps the evaluator to determine whether a program fails because of a) program failure--program did not reach the target populations, participants did not cooperate, etc.; or, b) theory failure--the program was perfectly executed bu the process did not "cause" the desired outcome.[2]

Practice Science and Theory

Sociological theory attempts "to provide systematic explanations and predictions relating to the nature, patterns, and dynamics of human social interaction."[3] Harold Lewis makes the following distinction between "theoretical science" and "practice science":

> Theoretical sciences serve an orienting function, locating the practitioner in time and place and pointing him in relevant directions. They suggest natural and societal constraints to be heeded, lest energies be wasted in trying to change what will not or ought not be changed. Practice sciences, in contrast, are concerned with the how of practice, prescribing purposeful actions.[4]

Lewis' description of practice science is akin to what is known as normative theory, viz., a set of interrelated propositions that prescribe the means of attaining certain goals; normative theory is not scientific theory: it selects principles from scientific theory and formulates them in a value-and-action oriented framework.[5]

Related to theories are "models"--a pattern of relationships "which is found in some way to imitate, duplicate, or analagously illustrate a pattern of relationships in one's observations of the world, such as patterns

in social behavior or social structure."[6] Inkeles, in his classic monograph What is Sociology?, states that no one model captures all facets of social reality; a particular model suggests relevant data and focuses attention to specific variables; and, a model is never true or false but only "useful or useless, stimulating or uninteresting, fruitful or sterile."[7]

The following theories and models were considered prior to the staff advisor's decision: that a hospital-based parents association could be an effective and efficient means to obtain a specialized preschool program and an "institutionalized" group within the hospital: (1) the prerequisites of applied research; (2) exchange theory and the norm of reciprocity; (3) linkages which connect bureaucracies and families; (4) introducing change in organizations; (5) strategies of accommodation, e.g., locality/community development; and, (6) personal and social determinants of voluntary association participation.

Prerequisites of Applied Research

Two articles recently appeared on the pages of The New York Times which attempted to explain "why" certain

phenomena occur. On the Op-Ed page, Sidney Hook, an eminent philosopher, concluded that it is "luck," in the final analysis, which is responsible for what occurs in our lives.[8] On the other hand, Dr. Iben Browning, a climatologist, claims that it is the drastic climatic shifts which shape the world's food production, economic stability and social order.[9]

Without questioning the validity of Dr. Hook's concept of "luck" as a major determinant of the human condition or the credibility of Dr. Browning's hypothesis that the world's economy and the world's social stability are directly related to "climatic changes," the applied researcher can only conclude that though both luck and climatic changes, may, in fact, be the most critical variables for an adequate explanation of the human condition, they lack practicality. As Alvin W. Gouldner has stated so clearly and crisply, "Thus the applied social scientist is concerned not merely with identifying predictively potent independent variables, but also with discovering some that are accessible to control."[10] Over and beyond "accessibility" and "control" are other criteria which the applied researcher must take into account: (a) values--would the

manipulation of a particular variable violate a cherished community norm or value; (b) cost--would the cost of manipulating this or that variable outweigh the resulting benefits or is the cost of a particular resource too costly for the researcher; and, (c) entry--since there are many different paths to the resolution of a social problem, the applied researcher must determine whether to manipulate certain variables directly (frontally) to reach a particular goal (usually where he has sufficient power to do so) or to reach the goal by the manipulation of more distantly removed variables.[11] Another consideration which must be taken into account is whether or not the independent variable (the program) will have unanticipated (or anticipated but unintended) consequences. As Carol Weiss has noted:

> The evaluator has to keep an eye on the "other" consequences of the program he's studying. Although decision makers have not articulated them as goals, he must unearth and study consequences that have significant impact on people and systems. Like the formulation of goals, this exercise requires thought and attention.[12]

Exchange Theory and Norm of Reciprocity

According to Alvin W. Gouldner, the norm of reciprocity involves two interrelated, minimal demands:

(1) people should help those who have helped them, and, (2) people should not injure those who have helped them.[13] In other words, we owe people not on the basis of their humanity or their social position but on the basis of their previous actions. The implication is that if you want people to help you, you have to help them.

Gouldner suggests that the norm of reciprocity is a starting mechanism, that is, it allows persons (or parties) to initiate new social systems: because it gives each party the confidence that there will be a fair exchange of resources. Gouldner states, ". . . The norm obliges the one who first received a benefit to repay it at some time; it thus provides some realistic grounds for confidence, in the one who first parts with his valuables, that he will be repaid."[14]

Whereas the norm of reciprocity assumes that the parties involved will have the capacity to provide the other with resources either in the present or at some time in the future, the "norm of beneficience"[15] requires that help be given on the basis of <u>need</u>; this norm is also viewed as a starting mechanism: to initiate social interaction. Using the automobile as a metaphor, Gouldner shows

the interrelatedness of both norms, ". . . The norm of beneficience is an ignition key that activates the starting engine (the norm of reciprocity) which, in turn, gets the motor--the ongoing cycle of mutual exchange--to turn over."[16]

What resources does each party require? Tension and conflict will be pervasive if the various actors within a social system want <u>particular</u> assets (which belong to specific actors) rather than a certain <u>class</u> of assets. To want particular resources is to engage in a zero-sum game: resources can only be accumulated by taking them from another: to win means that someone else has to lose. To want resources but not necessarily the identical resources which belong to the other eliminates the tension-laden zero-sum game.

The exchange theory of social organization is based on the "self-interests of actors who are seeking benefits through reciprocal exchanges with others, but over time these processes develop into stable patterns of social order . . . toward which the participants are committed."[17] The exchange theory rests on the following assumptions:[18]

a) activity is goal directed;

b) activities involve cost to the actor: time, energy, or resources expended;

c) actors want economy: the benefits should outweigh the cost;

d) activities which tend to produce results (benefits outweigh the cost) are usually perpetuated through time.

Harold Weissman specifies the various types of rewards participants (individuals as well as organizations) can obtain as they engage in social interaction:[19]

a) Emotional (friendship, praise, self-esteem);

b) Services that the association produces (e.g., a new school, more police protection);

c) Ideological--such as being a good American or a good Christian;

d) Negotiable--in systems other than the particular association, such as getting oneself in the public eye or enhancing the prestige of one's church or ethnic group.

An association, according to Weissman, can vary the quantity and quality of the aforementioned rewards by manipulating

its goals, procedures, or structure.[20] Such manipulation becomes necessary since people are willing to invest their resources (cost) if and only if there are compensating rewards. For example, since service rewards (e.g., obtaining a specialized preschool program) may take a considerable time to be produced, participants usually require some other forms of rewards to give them the motivation to continue to participate in the association. Unless the association can offer these other rewards, recruitment of new participants will be most difficult.

Voluntary and Auxiliary Associations

An association is a social organization that is created to achieve relatively specific and limited goals. Eugene Litwak considers a local voluntary association a good bridge or linkage between the "grass roots" and "bureaucracies" because (i) a voluntary association closely resembles the structure of the family unit; and, (ii) the creation of a voluntary association does not usually require a heavy investment of resources: and specialized knowledge can be learned in the process of doing (i.e., reaching certain goals).[21]

An auxiliary association such as a Parents Association is attached to a formal organization (bureaucracy): sponsored by the formal organization: and has a quasi-legal status within the organization.[22] An auxiliary association has the following advantages; it can accommodate a large number of persons; it requires a moderate amount of expertise; it can offer rewards through the prestige of offices held, public recognition, etc.,; and it appears to be most effective when the participants already support the formal organization's goals.

Over and beyond these aforementioned advantages, an auxiliary association is capable of flexibility in terms of its goals, structure and procedures. It has the following dimensions:

a) interaction can vary from intimate and informal to formal;

b) limited membership or unlimited membership;

c) local or nonlocal participants;

d) may vary in the degree to which the members are focused on the goals of the sponsoring organization;

e) frequency of meetings;

f) can maintain functional autonomy or be completely

dependent on the formal organization for resources (e.g., financial, labor, equipment).

Although an auxiliary association represents, at least in principle, an ideal structure for the collaboration between professional (bureaucracy) and parents (community/family), conflict and tension are inherent: because there is the possibility for either the auxiliary or the formal organization to take control (e.g., in some schools Parent Teacher Associations are do-nothing auxiliary associations because the school's administrative staff limits the resources available to the auxiliary group, or in some instances, a P.T.A. becomes so powerful that the administration feels compelled to consult the auxiliary group on even trivial decisions). In most cases, the formal organization controls the auxiliary rather than the reverse; and in most cases, a formal organization finds it more difficult to take control of a group outside its boundaries.

Introducing Change in Organizations

Change in an organization can come from either the external environment or from within the internal environment of the organization.[23] The external environment

consists of: a) the natural environment, b) population trends, c) technology, d) the human being--motivation and intellectual capacity, e) social environment--includes all other organizations with which the particular association comes into contact. The internal environment may involve: a') disregard or inadequate fulfillment of organizational needs, b') differences in activities and power among partially autonomous subunits, c') allocation of the benefits of organizational functioning.

There is no absolute standard by which to measure any given change as either fundamental or merely a routine adjustment. Olsen makes the following observation:

> This distinction between change "within" and "of" organizations is admittedly arbitrary, depending on which features of the organization are taken to be crucial and which merely peripheral, and on how much variation can occur in a key feature before it is considered to have changed. . . .[24]

The key features of an organization usually includes its boundaries, patterns of social order, decision-making process, predominant values, etc. Any change which has a decisive impact (positive or negative) on any of these key features can be considered a change "of" rather than a change "within."

Change within an organization can be triggered by

the process of the organization's subunits attempting to gain their own goals. As subunits (departments, bureaus, divisions) exercise power in relation to other subunits--i.e., procuring resources--both the subunit(s) and the larger organization are likely to change. The degree to which the change may spread throughout the organization or has a decisive impact on the key features within the organization depends on the amount of power exercised by the given subunit. In other words, the more powerful the Parents Association the greater will be its effects (e.g., the spread) of the change on other parts of the organization.

Any change introduced into an organization, irrespective of its source, will probably meet with resistance in varying degrees from within the organization. It is not necessarily human perversity which creates 'resistance to change.' Over a period of time an organization creates a shared social order and a shared culture; any change or innovation, particularly if it affects a key feature, will be perceived by some as destructive rather than beneficial to the organization.

Community Development

The process by which 'people help themselves' through rational discourse and reasonable action is a form of community organization which has been traditionally referred to as community or locality development. It is a process (or method) which encourages the given participants to accept the proposition that they as citizens possess the power to either alter, change, modify or overhaul any problematic situation in which they find themselves. Only recently an article entitled, "Give The People A Vision" by Rev. Jesse L. Jackson (an associate of the late Rev. Dr. Martin Luther King, Jr.) appeared in the Sunday New York Times Magazine, accentuated the thesis that more laws or more government programs will not substantially reduce the misery experienced by the Black community.[25] He believes that the onus for improvement (be it schools, poverty, crime in local neighborhoods, etc.) rests on the shoulders of the Black community--not on the government nor on the charity or good will of the white community. The article concludes with the following passionate appeal for self-help efforts:

> The first and immediate task for American blacks is to rise up from the decadence in which we find ourselves in the cities, and to do so by the force of our will, our intellect, our energy and our faith in ourselves. It is a historic opportunity we cannot afford to miss.[26]

In community development, the participant is perceived as the most significant and critical resource.[27,28] There is the recognition that often a professional or change-agent is required to guide or to enable a group--typically small groups--to develop the skills that are required to reach certain goals (e.g., obtaining a service). As the group begins to acquire organizational or communication skills and as the participants begin to experience a sense of accomplishment (i.e., achieving their goals), the professional can, in accordance with the precepts of community development, withdraw: so that the participants can begin to accept more and more the responsibility for their actions.

Community development is both a method and an end in of itself. It is a method/strategy because it endorses a particular approach to resolve social problems: a small group of citizens/consumers working together with a professional engage in a problem-solving process: which is then followed by a course of action. The implication is

that the participants share a set of common perceptions as to the definition of the problem as well as the means to resolve the problem. Community development represents a 'strategy of accommodation' or a method which relies on consensus. Whereas concurrence (or rational problem-solving) is always employed, and negotiation (there may be disagreement about either goals or means or both but each party is willing to reach a reasonable agreement through give-and-take) sometimes used, contest is rarely employed (open confrontation is a primary tactic and victory is the goal).

Community development is an end in of itself to the extent that it emphasizes the process through which participants learn the skills of citizenship and they internalize democratic attitudes; the achievement of specific (task) goals is not the sine qua non. What is essential is that the participants feel less alienated from the democratic political process. In other words, what really counts is the process of learning rather than any particular outcome, though successful outcomes are needed to sustain this process of learning. What counts is that people begin to feel that they have some clout in a

complex and complicated world.

Every strategy generates an array of tactics. In their book Introducing Social Change: A Manual For Community Development, Arensberg and Niehoff list a variety of tactics which are in consonance with the ideology of community development:[29]

1. establishment of communication channels with the target of recipient population;

2. selecting an innovation which is highly desired by the target population;

3. adopting the innovation to the existing cultural pattern;

4. flexibility--modify the program or innovation if it meets with community resistance;

5. people should participate--by contributing their time, labor so that the innovation or project will continue even after the professional withdraws from the project;

6. timing--to provide a service or to introduce an innovation when it is considered vital and critical to the community; sometimes a crisis is the best time to get a favorable hearing for an idea;

7. selection of an innovation or project:

   a) adaptive--a modification of a set of existing beliefs or practices (e.g., a community development project may be the improvement of existing houses or roads)

   b) additive--the community or target population will be getting what it never had before

c) replacement--the innovation is to replace a set of existing beliefs or practices

A replacement innovation is the most problematic since there is the potential for a clash of values.

Paul Kurzman, in describing the experiences of civil rights organizers in the South in the 1960's at the height of the civil rights struggle, proffers three phases which oppressed people have to pass through before they are able to gain the confidence and conviction that they do in fact possess the power/skill/influence to bring about social change.[30]

Phase 1. The organizer demonstrates that s/he has no fear in either confronting or negotiating with the establishment and that change is indeed possible and that the outcome of such confrontation is not as tragic as is often imagined. The essential ingredient is that the citizens who will eventually rely less and less on the organizer have the opportunity to observe the organizer in action as he confronts or negotiates with the system.

Phase 2. A transition where the organizer moves away from his or her advocacy model to a community development model: the transmission of knowledge and development of leadership within the client group.

Phase 3. The organizer (or staff person) assumes the role of consultant on technical matters and "frequently as an agent for continued leadership development and training within the group."

Participation in Associations

Although our country has often been characterized as a nation of joiners (because there are countless voluntary associations of all sizes and shapes), not every member of an association is an active participant; some people pay their dues but never go to meetings or only go once or twice a year; some join committees; others run for office. In other words, "participation" is a difficult variable to operationalize. What is more difficult to determine than the definition is what motivates or prompts people to participate. Research on the personal/social determinants of participation within associations have arrived at the following empirical generalizations:[31]

1. Participation is affected by an individual's social background:

a) life-cycle stage--e.g., parents have a higher rate of participation than adults without children;

b) socioeconomic status--higher rates of partici-

pation when a person possesses a good occupation, college background, home ownership;

c) sex, race, ethnicity can have an impact on participation;

d) formal organizational affiliations and roles have an impact;

e) residence and length of time resident stays in a given location have an impact on participation;

2. Socioeconomic level of a given community--If an individual with (say) a limited educational background lives in a community of high socioeconomic status, this individual will probably participate more than a highly educated person who may live in a community with less socioeconomic status;

3. Eligibility (formal and informal) requirements for membership can either induce or prevent participation;

4. Rewards. ". . . People are more likely to participate actively when their participation will make a difference, when they feel their efforts may help to influence a decision, establish a program, attain a goal, and, in general, bring about a state of affairs they want to gain. . . ."[32]

5. Organizational factors--the degree to which the association encourages participation is an important variable;

6. Personal skills such as verbal abilities, general intelligence, numerical abilities, social skills: there is a positive correlation between high verbal measures of intelligence and high rates of membership and participation.

The creation of an auxiliary association (Parents Association)--a hospital-based group--was based on the following value preferences and descriptive hypotheses*:

Value A. That consumers of services (or parents of developmentally handicapped children) ought to participate in the process of obtaining a service: because in a democracy citizens qua citizens should participate in as many aspects of life which either directly or indirectly affect

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*A value preference states what ought to be but an ought cannot be automatically or logically derived from a proposition of what is. A descriptive hypothesis does not proffer causal connections between independent and dependent variables but only stipulates 'what happens' when certain conditions exist. An analogy from chemistry--a descriptive hypothesis would state what happens when sodium and chloride are mixed but not 'how' or 'why' it happens.

their own situation: because the opinions of experts should be counterbalanced by the opinions of those persons/ consumers of the service so that the service offered will have a greater probability of being utilized by the population for whom it was intially created.

Value B. That wherever possible and whenever feasible the professional establishment and the lay community should work collaboratively: because social work philosophy gives a greater preference to efforts which generate cooperation rather than conflict: because social/ health/educational services often require for purposes of survival (particularly during this year of fiscal stringency) as many coalitions that can be formed. (In the next chapter a historical and sociological perspective will be presented of the self-help movement in the field of mental retardation--a history which only up until recently was riddled with tension between parent and professional.)

Descriptive Hypotheses

1. Based on theories of collective action and on the principles of democratic government, citizens/consumers can influence their social environment (which includes networks

of organizations) to the extent they are mobilized and organized into associations; and mobilization becomes feasible only to the extent that the participants can acquire the requisite resources (i.e., whatever is needed to reach a goal); one particular resource which can be helpful to an association is professional (technical or expert) expertise.

2. Organizational and political theory indicate that an association's capacity to influence relevant groups or key actors or both is not necessarily determined by its size (i.e., number of members) but by its capacity to obtain support from large numbers of people on those issues which are considered either crucial or controversial.

3. Organizational and administrative theory indicate that a hospital-based Parents Association can be a vehicle to obtain not only certain task goals but it can also be a structure for collaborative efforts between professional and consumers: where there is more consensus than contest.

4. Based on organizational theory as well on an exchange model, the Parents Association represents a compromise: the hospital would prefer not to consult with consumers on an ongoing basis and not to allow the parents to enter the organization's internal decision-making process

but it may tolerate a group which is not completely autonomous and is loyal to the goals of the formal organization.

5. The Parents Association can have the capacity to make an impact throughout the formal organization based on the fact that since many aspects (i.e., subsystems) of a hospital are interrelated and institutionalized, a change in any one part (in this instance the introduction of a new subsystem) will have ramifications throughout other parts or the whole organization; that the nature of the impact and its spread thrcughout the hospital is contingent on the amount of power exercised by the Association; that any given subsystem within an organization in the process of obtaining its goals must continuously take account of the limits, demands, and constraints imposed by the organization as a whole as by the larger social environment; that key features of an organization are difficult to change because they are the means the organization uses to perpetuate itself so that before any key feature (e.g., decision-making process) is tampered with or substantially altered, an organization will employ whatever maintenance devices to ward off the possibility of change; a "crisis" represents a good opportunity for change since the key actors in the organization may be looking for new ways to solve urgent problems.

6. Organizational theory would suggest that community development as a strategy to obtain social change (e.g., obtaining a new social/health/educational service) would be viewed as relatively non-threatening as compared to a 'social action' model and therefore tolerated) in a hospital: which has shown in the past that it not only fears but loathes militant-protest activities by autonomous grass roots organizations; that the role of the professional staff member as a "staff advisor" would also be acceptable and tolerated because the staff advisor would be expected to exert control as well as aid in such a way that the Association's goals and the hospital's goals are congruent.

7. Research on personal and social determinants of participation suggests that parents whose children have not been accepted into specialized preschool programs would represent a highly motivated group: who would be ready, willing, or prepared to participate in an association whose goal is the creation of such a specialized program. In other words, people who need the program the most would be willing to participate in accordance to an exchange theory model: if they perceive that the association's major interest is creating a program for their children.

Notes

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CHAPTER III

A SOCIOLOGICAL AND HISTORICAL ANALYSIS OF PARENT ASSOCIATIONS FOR THE MENTALLY RETARDED

Growth of Parent Associations After World War II

The growth of parent associations (which includes both formal groups as well as ad hoc groups) was rapid after World War II (WW II). In the United States the National Association for Retarded Children was founded in 1949.[1] Associations also sprung up in India, Peru, Tunisia and Korea.[2] Typically, parent associations* were

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*The following is an excerpt from unpublished material distributed by Project HOPE, Ltd. at their Conference on Early Childhood Education for Retarded Children on 3/21/75 at P.S. 230 in Brooklyn: "Project HOPE saw its beginnings on June 5, 1972. At the time a small group of parents of Down's Syndrome pre-schoolers was invited to attend a series of rap sessions at the Developmental Clinic of the Jewish Hospital and Medical Center of Brooklyn. Liability insurance was provided . . . and we pooled our resources and rented a bus to transport the children and cooperating parents to school and back home three mornings a week. Our journey . . . to our presently functioning program . . . has been exciting, at times exhausting, challenging, and rewarding. We have fought vigorously for our children."

and are being organized in the following manner: first, two or three interested parents get together and meet in each other's home. Secondly, they publicize their meeting place and time and involve other parents to join them in their fight for more services to their retarded children. Finally, from these informal ad hoc groups are derived formal associations with membership requirements, an executive board, national and regional offices, standing committees, professional staff, and so on.

Bernard Farber proffers a hypothesis to explain why this rapid growth took place immediately after WW II: as more and more severely and profoundly retarded children were being born to middle-class parents at a time of economic prosperity, these parents had an incentive to organize into associations to provide and obtain needed services, particularly educational programs, for their children.[3] The two significant variables are economic prosperity and middle-class parents. Prosperity stimulated optimism that communities would support services for retarded children. And middle-class individuals possessed the organization skills and political clout to obtain these services.

Prior to WW II, America had been preoccupied with other dominant social movements such as temperance and the nativistic movement. Farber states, "Since there is always a dominant cause and the causes of mental retardation are complex, it becomes difficult to focus attention on mental retardation."[4] The fact that many parent associations for the mentally retarded were (and still are!) initiated and organized by the middle-class is more than just an interesting historical datum. Because many of the children were either profoundly or severely retarded, parent associations promulgated a medical orientation. Profoundly and severely retarded children are often retarded as a result of either prenatal, perinatal, or post natal injuries. This new medical focus represented a drastic departure from the previous policy of social control.[5] In the late 19th century and early 20th century, America's policy towards the retarded ("mentally defective" or "feeble" minded) had been based on the policy that society had to be protected from the retarded individual. What flowed from this social control policy were large, dehumanized institutions located away, or hidden from, communities. Sterilization laws, based on the principles of eugenics, also resulted from the social control policy.

In 1912 The Kallikak Family was published. It made an immediate impression on the public. Henry H. Goddard, the author, used statistics to demonstrate how one family produced generations of degenerates, prostitutes, alcoholics, and epileptics. He argued that feebleminded-ness is inherited and that the feebleminded are criminals. In 1915, Dugdale wrote The Jukes, which suggested the same connection between crime and the mentally defective. Even when the policy changed from "protection of society" to "protection of the retarded" it did not change too much programmatically. The basic assumption was still that the retarded could not learn or improve. Ergo, they did not belong at home but in institutions.

Parent associations with their strong medical focus presented a completely contrary view. A retarded child can learn. Retardation is not always inherited, that it can be prevented in the same way a disease can be prevented. For example, a child with hydrocephalus (a large head due to excess fluid) either died or became a severely retarded individual. A shunt was invented and neurosurgeons could operate and place the shunt into the head to siphon the fluid into other organs of the body. More hydrocephalic children lived and some developed only moderately or even

mild reatrdation. An important consequence of this new medical focus was research into the causes of retardation.

The Evolutionary Growth of Parent Associations

Some observers of parent associations have noted that these groups are inclined to develop and grow in a very predictable manner as if each association develops in accordance with definite laws of organizational growth. Such a view of organizational development is akin to a theory of evolution by steps; namely, over a period of time, growth takes place in a stair-step fashion. There are discontinuities but each stage (or higher level) is different from the previous one. There is no implicit (value) assumption that each later or higher stage is 'better' than the previous one.

Wolf Wolfensberger in a lucid and insightful monograph, The Third Stage In the Evolution Of Voluntary Associations For The Mentally Retarded explains that the goals of an association undergo an evolution in three stages:[6]

Stage 1. Members initiated, fund and operate services.

Stage 2. Public funds are accepted to operate association services.

Transfer of some services to public or private agencies.

The initiation of new services.

In some cases, the complete transfer of all professional-technical services to public or private agencies. The focus is on obtaining rather than providing services.

Stage 3. Pure change-agentry role. Monitoring of the publicly-funded service system.

In this stage, parent associations no longer provide or obtain services. They may sponsor demonstration or pilot projects, which are later transferred to other auspices.

A parent association which has reached this stage has advocacy functions such as public attitude change; monitoring services; legislative and governmental action; liason with generic services; manpower development.

He also suggests an intriguing hypothesis regarding the stages of development of an association and the psychological development of the parents. A parent who is only concerned about his own child is motivated to join an association that can meet his urgent needs--e.g., to get the child into a special school. Parents who are ready to consider the plight of other children will work for an association whose goal is obtaining services for families with similar problems. Only parents who can begin to see

that the needs of their handicapped child is linked to all human services are ready to join an association which supports advocacy* and the monitoring of the entire delivery system.[7]

The impetus for Stage 1 is the reality that unless, they, the parents organize and pressure their respective communities, there would be very few services for the retarded child. By sheer hard work and often with sweat and tears, services have been successfully obtained and staffed by parents. But once services are in existence they have to continue to service future client populations. Services have to change with changing conditions and some have to expand to reach larger target populations. And in some instances new services must be created (or designed) to deal with new problems. Successful parent associations soon realize that private fund raising does not provide sufficient funds to cover operating expenses. Public funds

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*For purposes of this study, advocacy is broadly defined as ". . . intervention on behalf of handicapped children in relation to those services and institutions that impinge on their lives." See Child Advocacy: Report of a National Baseline Study by Alfred J. Kahn, Sheila Kamerman and Brenda G. McGowan.

become a necessity! There are basically two propelling reasons why a parent association begins to request public monies:

> Thus, there were two reasons to pursue support of services from public monies: the fact that without it, there simply would never be enough services; and the growing ideological conviction that a major needed service should be provided as a matter of right, rather than charity.[8]

Wolfensberger notes that few parent associations move from Stage 1 to Stage 2, and only one or two have actually moved onto Stage 3. The difference between the last two stages is from <u>obtaining</u> to the <u>monitoring</u> of services. Wolfensberger describes this change as follows:

> Herewith, I propose that the shift from obtaining more and more new services on the one hand, to the forceful monitoring, of services on the other, will be the third stage in the evolution of adaptive associations, and will be one of the major manifestations of change agentry particularly in those societies where the quantity of services is substantial.

The crucial variable is "substantial services." Since the initial impetus for the formation of associations is the lack of services, it is indeed unrealistic to expect parents to become complacent about the provision of services. They cannot be convinced that any given community, on its own volition, will provide services; to the contrary, they believe that a community will support services for the

retarded only after parents organize into associations and pressure and pressure until a service is eventually given.

A parent association is reluctant to surrender what has taken "sweat and tears" to create. No organization wants to eliminate itself. The first law of organizations may be stated as follows: survival! The classic example is the National Foundation for Infant Paralysis, which decided, after the discovery and success of the polio vaccine, to change its goal rather than dissolve. The Foundation went through a process of succession of goals.[10] Consequently, a parent association does not want to transfer its services to other auspices to assume advocacy functions. Stage 3 is more of a dream, a prospect rather than a realistic possibility. If parent associations for the mentally retarded do not monitor the delivery system, then who will?

Wolfensberger's interest in parent associations goes beyond theory building (e.g., stages of evolution). He wants to impart understanding to give both parents as well as professionals the ways and means of introducing effective planned change. He believes that parent associations should, by conscious choice, choose to assume advocacy functions.[11] It is interesting to note that Kahn

documents in Child Advocacy: Report Of a National Baseline Study that groups which are trying to wear the mantle of child advocacy are mostly interested in the "delivery of services" in terms of its adverse effects on children. He states, "And because the focus is on rights and entitlements, it is vital to make these service systems more accountable to consumers."[12] In other words, Wolfensberger would want parent associations to carry out the types of functions that Kahn describes. The National Welfare Rights Organization would be, for Wolfensberger, a prototype organization (in terms of its desire to make welfare more humane) for parent associations for the mentally retarded.

Although child advocacy has been (or becoming) a popular enterprise, parent associations for the retarded have shown little interest in the areas of accountability, evaluation, and monitoring of services to the retarded. Even in the few instances where parent associations have gone to court to affirm the "right to treatment" for the institutionalized retarded, they have been lax in doing the necessary legal follow-up. Yet Kahn's investigation showed that advocacy programs throughout the country consisted more of volunteers than professionals:

> Several kinds of programs place heavy emphasis on the use of volunteers. For example, citizen advocacy programs, a rapidly expanding network, believe that only volunteers can be totally accountable to the programs' clients.[13]

Kahn admits bewilderment as to why volunteers represent such a disproportionate number within child advocacy programs. He cannot see any obvious link(s) between the use of volunteers and other organizational variables such as goals, structure, or process.

Perhaps the significant variable is whether the organization is new or established. This may explain why parent associations, whose majority are parent volunteers, do not get involved with monitoring and evaluation functions. Parent associations are not too unlike trade unions whose goal is more and more and more! Kahn is cognizant that newness is an asset, "One impression is that the most effective new programs defined their goals first and then developed structure and interventive strategies in accordance with these goals. Of course, this sequence is not feasible for an existing agency that takes on advocacy."[14] Established parent associations have goals which are fixed: they are not prepared to undergo a metamorphosis.

To sum up: 1) The majority of parent associations are either operating or obtaining services or doing both. Only one or two associations have been reported in the professional literature of having given up their services to assume advocacy and monitoring functions. 2) Child advocacy programs have documented the inadequacies of the way our communities deliver services to children. Parent associations for the mentally retarded have been less concerned with monitoring and evaluating the effectiveness and efficiency of programs. 3) Whereas volunteers predominate in child advocacy programs, parent associations are busy operating sheltered workshops, camp programs, clinics, and hostels. 4) A crucial variable is whether an organization is new or established. A new group has more freedom to adopt advocacy goals. Parent associations have a vested interest in keeping that which they struggled for: services for the retarded child. And services for the retarded have not reached the "substantial" stage at which time parents can feel secure to consider advocacy goals.

Volunteers and Professionals

The relationship between volunteers and social service professionals has been defined and redefined over

the years. It is a relationship that refuses to remain static. Walter I. Trattner, who has written a very readable history of social welfare in America, has noted that as soon as charity work demanded systematic fact gathering and the scientific interpretation of data, agencies needed people who were trained and possessed expertise. Activity based on scientific knowledge becomes more important than good intentions. A cause requires zeal; a function requires intelligence.[15] Whereas in the middle of the 19th century the "charity worker" and the "volunteer" was synonymous, in the early 20th century "voluntarism" was no longer a civic duty. It was a privilege granted by agencies.[16] The reversal in roles represented a major shift in the distribution of power to the professional.

Parent associations are still struggling with this issue--who does what? professional or parent? who is in control? At an international conference (1967) on parent associations for the mentally retarded a statement was adoped which endorsed the principle that an association should have a majority of parents of the retarded as its members, and that these parents must remain in control at every level of the association.[17] For example, in the

National Association for Retarded Children (NARC) no paid employee is eligible to hold any elective office.[18] The justification for parent control is simple and clear: since an association for the mentally retarded is almost always initiated by parents of the retarded, then parents ipso facto have the right to direct (or dictate) policy.

The role strain between the professional and the parent must be viewed within a social context: since roles involve more than just one person. Alfred Katz implicitly considers the tension between parent and professional as inevitable: because associations are constrained by their dynamics of group/organization psychology. His study of parent associations reveal a predictable evolution in five phases:[19]

1. ORIGIN--Two or more persons get together to solve a common problem.

2. INFORMAL ORGANIZATIONAL STAGE--Volunteer activity is pragmatic and improvised.

3. EMERGENCE OF LEADERSHIP--Certain functions become identified with certain individuals; activities become routine.

4. BEGINNINGS OF FORMAL ORGANIZATION--More structure is developed and codified in rules and bylaws.

5. BEGINNINGS OF PROFESSIONALIZATION--The leadership group may find it necessary to give up some of its

> own routine organizational functions to paid staff workers (first clerical staff followed by professional social workers).

Farber, on the other hand, analyzes associations not as an anthropologist (like Katz) but as a sociologist (functionalism). He notes that associations develop federated rather than corporate structures. He states, "When local units gather to combine into a national organization, a federation type of structure usually develops."[20] This observation can be construed as a historical datum. But he proffers a sociological explanation:

> Since the mentally retarded represent a diversity of clinical symptoms and social backgrounds, it seems unlikely that a corporate structure could have worked efficiently in handling the numerous problems in both ideology and social relations associated with mental retardation. [Underlining is mine.][21]

Although this explanation does not purport to answer the question of how the tension between the professional and the parent developed, it suggests an answer. Parent associations have been "problem oriented" because they want services for specific problem areas. Professionals, on the other hand, are more "issue" oriented. They are more equipped, by training, to transcend the immediate problem. Parents do not want to involve themselves in an activity

that does not have some immediate and direct impact on their children.

This difference in perspective has another dimension. The professional is viewed by the parent as a person who is after power and status rather than a person who has community sanction to deliver a service.[22] From this perspective, parent associations, historically, have answered two basic service delivery questions in the following manner:

QUESTION	ANSWER
1. Where shall authority and control rest?	Parents
2. Who shall carry out the different tasks to be performed?	Parents, and--if dictated by public contract--professionals

The operation of a service requires "time" and in a parent association (or any voluntary association) time or amount of participation equals power. The professional is paid to have the time to work for the agency; the volunteer-parent must cope with conflicting (i.e., family, job, avocation) demands and loyalties on his time. Typically, there is an extraordinary amount of participation at the time the association is in the process of being formed

(Katz's phases 1 to 4). It may be a truism to state that all beginnings are difficult as well as exciting. However, as the association becomes more established there is a drastic drop in participation; the association finds itself with what is commonly known as a "paper membership." Time (which equals money), then, becomes a countervailing force which favors the professional. Perhaps it is the parents' awareness that participation equals power (in a voluntary association) that parents themselves begin to occupy paid or staff positions.

Over and beyond the difference between "issue" (professional) and "problem" (parents) orientations, Thomas Borkman suggests that the source of antipathy between members of self-help groups and the professional community is "experiential knowledge" versus "professional" knowledge. According to Borkman:

> There are also major differences between professional and experiential knowledge. In contrast to professional information, experiential knowledge is (1) pragmatic rather than theoretical or scientific, (2) oriented to here-and-now action rather than to the long-term development and systematic accumulation of knowledge, and (3) holestic and total rather than segmented.[23]

Some self-help groups, like Alcholics Anonymous, rely solely on their members for policy-making and program-

ming. Whereas other self-help groups, like stutterers' self-help groups, make extensive use of professional assistance. A third type of group (stutterer clubs in Sweden) will obtain knowledge and assistance irrespective of source (experiential or professional) and has no special membership category for "professionals."[24]

This section consisted of an historical and sociological analysis of parent associations for the mentally retarded. Some of the major points are:

1. In the field of mental retardation parents are expected to organize and to pressure their respective communities to support services for the retarded.

2. Parent associations are primarily a middle-class movement with a major interest in the profoundly and severely retarded (the minority of the retarded).

3. Associations created a system's change when they introduced a medical focus. Up until World War II, social control was the overt policy for the retarded.

4. Associations move through stages of evolution. The stage of monitoring and evaluating services (Stage 3) is rarely reached; it is more of a goal or a dream than a reality. Associations have a vested interest in either

operating or obtaining services (Stages 1 & 2). In a field where there is a huge service gap parent associations cannot justify the transfer of their services to different auspices.

5. Parent Associations for the retarded are usually established associations and they find it more difficult to redefine their goals.

6. Katz describes five predictable phases that every parent association experiences. It is at Phase 5 that professionals (first clerical) are hired because the work-activity becomes routine.

Two other reasons why professionals are employed:

a) only public funds can support a variety of services;

b) public funds ensure that the service is a right rather than a gift.

7. Professionals and volunteers have competed with each other for power and roles reversed when knowledge became more important (valued) than good intentions.

8. Parent associations have historically endorsed the principle that power or control belongs to parents: because it is the parents who started and governed the association.

9. Parents are "problem" oriented; professionals are more "issue" oriented. There are also differences between professional and experiential knowledge.

10. Parents view professionals as being more interested in power and status for themselves rather than as persons with service functions.

11. A countervailing force is time; time or participation equals power and money. As soon as associations become successful, participation drops. It is usually at this point that professionals assume more and more responsibility.

Parents do get together and organize like the parents of Project HOPE, Ltd. in Brooklyn.[25] They do succeed in operating and obtaining services for the retarded. Parent associations are now trying to amend Education Law 4407 to mandate rather than render permissible public school education for children from three to five years. An exciting chapter for parent associations and public school education is unfolding. Some local community school districts have already accepted in principle the responsibility to educate preschoolers. If the law is amended, parent associations would have contributed to a fundamental change: because <u>all</u> preschool handicapped children would benefit.

Notes

1. Alfred H. Katz, "Self-Help Organizations and Volunteer Participation in Social Welfare," Social Work 15 (January 1970): 51-60.

2. Rosemary F. Dybwad, "The Voluntary Association on the International Scene," Mental Retardation and Developmental Disabilities: An Annual Review VI, ed. Joseph Wortis (New York: Burnner/Mazel, 1975), pp. 273-289.

3. Bernard Farber, Mental Retardation: Its Social Context and Social Consequences (Boston: Houghton-Mifflin Company, 1968), p. 126.

4. Ibid., p. 125.

5. Ibid., p. 125.

6. Wolf Wolfensberger, The Third Stage in the Evolution of Voluntary Associations for the Mentally Retarded (Toronto: National Institute on Mental Retardation, 1973), p. 59.

7. Ibid., p. 44.

8. Ibid., p. 8.

9. Ibid., p. 24.

10. David L. Sills, "The Succession of Goals," in A Sociological Reader on Complex Organizations, ed. Amitai Etzioni (New York: Holt, Rinehart and Winston, Inc., 1961), pp. 175-187.

11. Wolfensberger, p. 24.

12. Alfred J. Kahn et al., Child Advocacy: Report of a National Baseline Study (Washington, D.C.: Health, Education, and Welfare, Office of Child Development, Children's Bureau, 1973), p. 61.

13. Ibid., p. 56.

14. Ibid., p. 102.

15. Porter R. Lee, Social Work as Cause and Function (New York: Columbia University Press, 1937), p. 5.

16. Walter I. Trattner, From Poor Law to Welfare State: A History of Social Welfare in America (New York: The Free Press, 1974), p. 92.

17. Dybwad, p. 278.

18. Farber, p. 126.

19. Katz, pp. 56-57.

20. Farber, p. 131.

21. Ibid., p. 131.

22. Neil Gilbert and Harry Specht, Dimensions of Social Welfare Policy (New Jersey: Prentice-Hall, Inc., 1974), p. 127.

23. Thomasina Borkman, "Experiential Knowledge: A New Concept for the Analysis of Self-Help Groups," Social Service Review 50 (September 1976): 449.

24. Ibid., p. 452.

25. Mary Last, "Parents of Disabled Bank on Education," Daily News, 9 February 1975, Brooklyn Living Section, p. 3B.

CHAPTER IV

PLANNING AND IMPLEMENTING THE PARENTS ASSOCIATION

Nature of Unmet Need

The Child Developmental Center at the hospital is contracted by the New York City Department of Mental Health and Mental Retardation to provide evaluation and treatment services for children from birth up until age sixteen who are either suspected of retardation or have already been certified by the school system as retarded, and who live within a specified geographical area.

In 1975, of the one hundred four (104) children serviced by the Developmental Center about 50% of the caseload were children five years of age or under.* During the summer of 1975, the professional staff as well as some of the parents began to experience and to articulate their

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*In the annual N.Y.C. Bureau of Mental Retardation reports (1973-1974, 1975-1976), preschool programs are recommended for each community though only one or two communities have such programs.

frustration that children from ages three to five, particularly those children who were in the range of moderate to profound retardation, were excluded from generic agencies located within the community. The five day care centers, Head Start as well as the Reading Readiness program (sponsored by the Board of Education and a private voluntary agency) "officially" accepted handicapped children into their respective programs; Head Start, for example, has been mandated by H.E.W. to include 10% handicapped children into its program.

But the stated policy is not always the actual policy. These generic child care agencies, though professing concern and commitment to handicapped children, successfully excluded retarded and developmentally disabled children through their restrictive (and discriminatory) intake policies.*

The Developmental Center also made referrals to specialized preschool programs outside its catchment area.

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*In 1975 and 1976, the generic agencies required that a preschool child be toilet trained as an eligibility requirement. Few retarded children are toilet trained by age 3 or 4.

Because these faculties possessed their own mandated catchment areas, so that preference was given to at-risk children in their own areas, referrals from the Center routinely got placed on a "waiting list." Three or four children were on such waiting lists from a year to two years.

Referrals from Center to child care agencies within its own catchment area or to specialized preschool programs outside of its catchment area (since no specialized preschool programs were available within the community) were either disapproved or are placed on waiting lists with indefinite waiting periods. Although the hospital in general and the Center in particular offered a variety of services to the retarded preschool child (e.g., speech therapy, occupational therapy, physical therapy, pediatric clinics); although the Center often referred preschool children to agencies which offer home-training programs (e.g., teaching a parent how to teach a self-help skill to a retarded child); both the Center's professional staff and the parents of the preschool children were convinced that only a specialized preschool program had the potential to offer (a) a socialization experience for

children who have been isolated and sheltered from other children; (b) systematic emotional, social, motor, and academic stimulation, administered through a trained early special education teacher.

In other words, the parents as well as the Center's professional staff felt that a treatment plan must not only include the recommendation of a preschool program but such a program must in fact be available and accessible to the children. That without a specialized program violence was being done to the policy of 'continuum of care' and to the concept of early intervention. That without such a program the children would not only suffer more intensely but their disabilities will become more complicated as the child becomes older and their chances to later succeed in public school (in special class placement) will become more problematic.

To sum up: Because preschool and nursery programs, for normal children in general as well as preschool programs for children with environmental deprivation and for children with developmental handicaps in particular, have been established and tested throughout the country since the middle '60's; and because the Center was mandated to

deliver a variety of services to developmentally handicapped children; its advocacy of a specialized preschool program for children within the community was considered by the professional staff and the parents not only "appropriate" but absolutely imperative.

Timeliness

In 1974 a social worker at the Developmental Center of Brooklyn Jewish Medical Center helped to organize a group of mothers of Down's Syndrome (Mongoloid) children for the purpose of obtaining a preschool program within their own local community.* Within a six month period, the parents incorporated and referred to themselves as Project HOPE. They were able to convince their local school district to start a preschool program in one of the district's public schools. This was considered an unprecedented success since public schools in New York State are not legally mandated to educate retarded children under five years of age.

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*A feature story appeared in the Sunday New York News on February 9, 1975, p. 3B.

The N.Y.C. Board of Education provided the teacher (supported by federal funds); and the parents, through their association, raised money (bazaars, flea markets, dinner dances, etc.) to purchase equipment (e.g., balance beams, mats, etc.) and transportation (minibus service) for the children to get to and from the program.

In addition to the success of Project HOPE, the Board of Education Bureau of Children With Retarded Mental Development (BCRMD) had already established the pattern of co-sponsoring special educational programs "with" as well as "within" hospital clinics.

Through its public relations material (newsletters, all-day conferences),* the Board of Education conveyed the message that it was (a) committed to the idea of early intervention for children with retardation and related developmental disabilities; and (b) committed to the idea that specialized preschool programs must be jointly sponsored and operated by the schools and centers for child development with support by parent associations.

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*See BCRMD, Early Childhood Programs, ed., Bebe Bernstein, Assistant Director (Board of Education of the City of New York, 65 Court Street, Brooklyn, N.Y. 11201), 1972.

There was no question about the "timeliness" of the need for a preschool program for developmentally handicapped children. It was the timeliness of this type of program which afforded the staff advisor the opportunity to test the feasibility on an auxiliary association as a vehicle to obtain this important educational program.

Appropriateness

Preschool programs for mentally retarded children already exist in Brooklyn, N.Y. under public and private auspices. Funding sources are varied: federal, city, and state, foundation grants, local school districts, etc. In Brooklyn, many preschool programs are affiliated with hospital child development centers; the center usually evaluates the child to determine the nature and the extent of the disability and it continues to monitor the child's development as s/he participates in the preschool program.

Since the Center at the hospital evaluates a large number of the developmentally disabled children on a daily basis; and since the Center has achieved a reputation of providing quality diagnostic and treatment services to the children and their families; there was the expectation

that local community agencies such as the school district, day care centers, and Head Start would perceive the Center's tilt to advocacy (i.e., for a preschool program) as a logical and reasonable development vis á vis the Center's own growth and development as an evaluation and treatment facility.

Program Design

The purpose of this project was the creation, with the assistance of a professional social worker, of an auxiliary-type group (Parents Association) whose ultimate goal would be the creation of a specialized preschool program within the hospital's catchment area. It was not expected that this ultimate goal would be accomplished within a six month time period (January-June 1976). What was anticipated, however, was that the Parents Association (PA) would engage in activities which could result in the acquisition of resources (funds, space, community interest, etc.) that in turn could be utilized for the operation of a specialized preschool program.

Whereas the primary purpose of the project was the creation and development of a hospital-based Parents

Association, a secondary purpose was to test the feasibility of implanting ("institutionalizing") a consumer group within the hospital. In other words, the social need for a preschool program presented an opportunity to create an organizational structure which would include the parents in the hospital's decision-making process: which in turn would not only make the decision-making process more democratic but would also result in more and better services for handicapped children.

The basic assumption was that an auxiliary association with the assistance of a professional social worker would act as a socio-political organization that would exert sufficient pressure on various constituencies within and outside of the local community to obtain specialized preschool program. A corollary to this basic assumption was that if the Parents Association was effective, then a preschool program would be obtained.

The planning for this project began as early as May 1975. The staff advisor recognized that he would need to establish credibility with various "gatekeepers" within the hospital before he would receive sanction to work with a hospital-based parents group. Since his employment

at the hospital in 1973, he has heard that the hospital's administration has looked askance at grass-roots community groups.

An opportunity to establish credibility presented itself in May 1975--the staff advisor was appointed by the Brooklyn Boro-Wide Council for Mental Retardation to be the spokesman "for the needs of the retarded" in the hospital's catchment area at a "town hall" meeting (sponsored by the N.Y.C. Commissioner of Mental Health and Mental Retardation). To prepare for that town hall meeting, the staff advisor convened a meeting of consumers and providers at the hospital so that he could incorporate their suggestions into his "presentation" to the Commissioner. This preliminary meeting was critical for the staff advisor because it was attended by the hospital's Director of the Department of Social Services as well as by the Affiliation Administrator and his Assistant Administrator. Like most municipal hospitals, this hospital had an affiliation contract with a private voluntary hospital. All the professional staff of the Developmental Center as well as the staff advisor were under the affiliation contract. The staff advisor was later told by the Director of Social

Services that all the administrators were pleased with the way he "handled" the meeting. Two days prior to this meeting, the Assistant Affiliation Administrator warned the staff advisor that he should ". . . be careful not to let the meeting get out of hand nor allow a lay group of people to dictate to the hospital." By the end of June 1975, the staff advisor achieved some "credibility" by demonstrating to the hospital that he can "handle" a community group meeting; that he possessed certain technical knowledge regarding the programmatic needs of the retarded; and that he can, more importantly work "responsibly" within a hospital-community framework.

In early 1975, the staff advisor sent out a brief proposal (see Appendix A) to three hospital administrators; the proposal outlined the creation of a Parents Association, with the target date of September 1975 for implementation (when parents and staff returned from their summer vacations). The Medical Director of the Developmental Center had a favorable reaction because she felt that the local community needed a specialized preschool program for developmentally handicapped preschool children; and she felt a "strong" Parents Association could either "raise

money" or act as an "advocate" for the Developmental Center, especially during a time of budgetary cutbacks. The Director of Social Services gave his "O.K." because the Medical Director of the Developmental Center had already given her approval: in addition, he gave his approval with the proviso that this project must not adversely effect the staff advisor's primary assignment as Coordinator, and Social Worker of the Developmental Center.

By the end of June 1975, the Medical Director of the Developmental Center, the Director of Social Service, the Director of Community Relations, and the Affiliation Administrators were all in agreement that the project was appropriate and that implementation could begin in September 1975. Throughout the months of May and June 1975, the staff advisor cultivated support for his project by meeting with various administrators informally on a one-to-one basis; he purposely avoided larger meetings because he feared that whereas an administrator might be comfortable talking positively about a hospital-based Parents Association on a one-to-one basis, s/he might become more negative about "militant" consumer groups if he had to face two or three of his colleagues at a

meeting. See Fig. 1 for a visual representation of the contractual (explicit and implicit) arrangements and Table 2 for significant professional and administrative personnel participation in this project.

During the summer months of July and August as well as September 1975, the staff advisor canvassed about fifteen mothers of handicapped preschool children to determine their interest in forming a Parents Association For Preschool Retarded and Developmentally Disabled Children. The majority expressed interest; however, many of them felt that they had so many clinic appointments that they did not know how they could find the time to participate. On September 12, 1975, a letter (drafted by the staff advisor) signed by the staff advisor and a parent (who later became the chairperson) was mailed to about fifteen parents who had handicapped preschool children. The letter informed the parents that they were invited to a meeting at which time they would begin to plan the creation of a hospital-based Parents Association. On September 22, 1975 only two parents attended the meeting. One of the reasons for this small attendance was that the letters were mailed on September 17 and the meeting was scheduled for September 22.

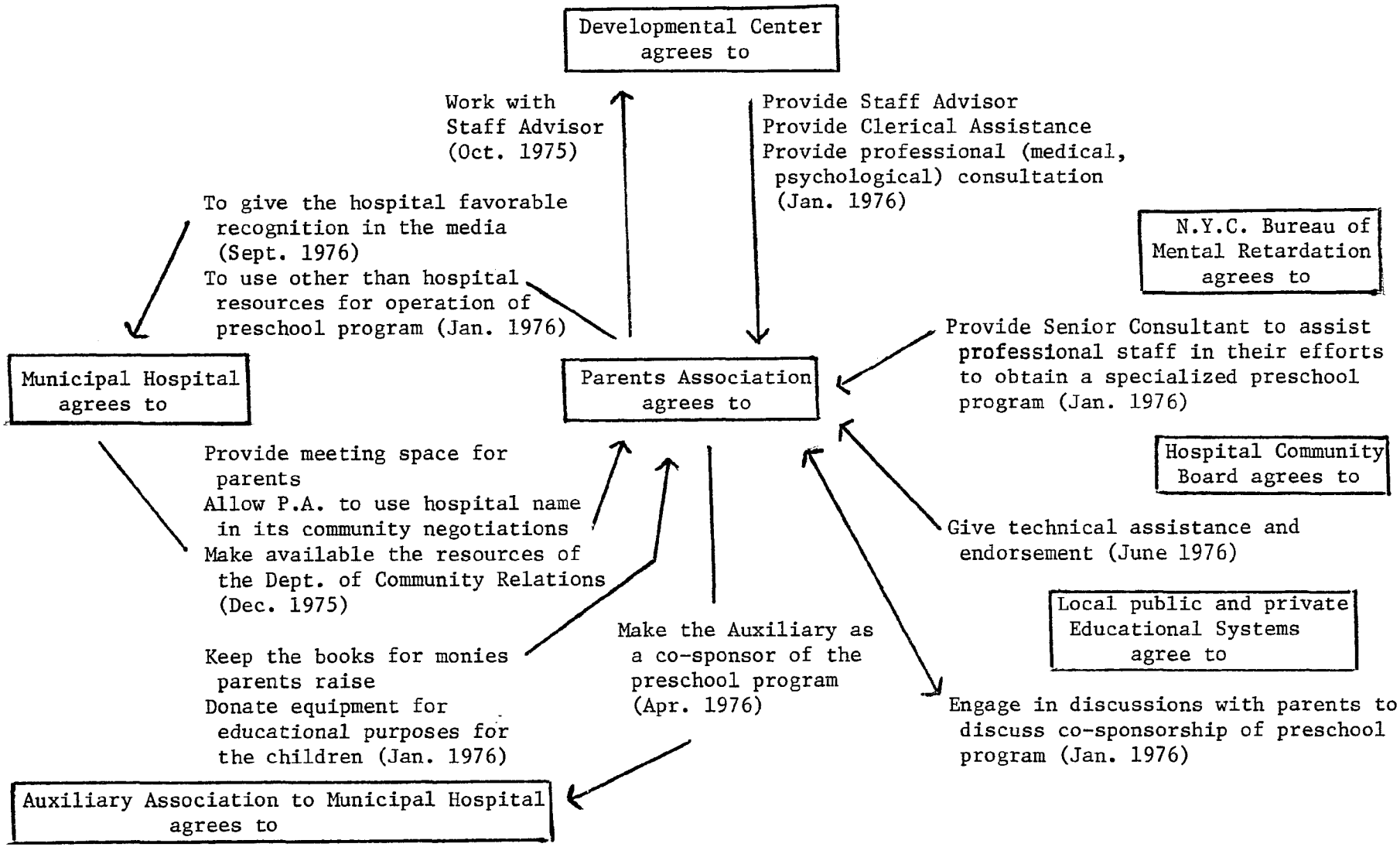

FIG. 1

CONTRACTUAL ARRANGEMENTS AMONG THE COOPERATING HOSPITAL UNITS AND COMMUNITY INSTITUTIONS (FROM JANUARY TO JUNE 1976)

TABLE 2

SIGNIFICANT PERSONNEL PARTICIPATING IN THE HOSPITAL-BASED PARENTS ASSOCIATION AND THEIR PRIMARY INSTITUTIONAL AFFILIATION

HOSPITAL DEPARTMENTS	QUASI-PUBLIC STRUCTURES	NEW YORK CITY DEPARTMENT OF MENTAL HEALTH AND MENTAL RETARDATION
1. Developmental Center a. Staff Advisor (Accountable to Affiliation, Administrator, Director of Dept. of Social Service, Center's Medical Director) b. Medical Director (Accountable to Chief, Pediatrics) 2. Chief, Pediatrics Department (Accountable to Medical Board, Affiliation Administrator) 3. Director Community Relations (Accountable to Executive Director) 4. Assistant Affiliation Administrator (Accountable to Affiliation Administrator) 5. Director of Department of Social Services (Accountable to Executive Director) 6. Affiliation Administrator (Accountable to Executive Director, Medical Board, Board of Trustees of Voluntary Hospital) 7. Executive Director (Accountable to Health and Hospitals Corporation, Community Board, Medical Board)	1. Auxiliary Association of Hospital 2. Community Board (September 1976)	1. Senior Consultant from the Bureau of Mental Retardation (Accountable to the Assistant Commissioner of Mental Retardation Services)

Throughout the months of October and November, the attendance at meetings consisted of only three and four mothers. A letter of commendation (drafted by the staff advisor but signed by the Chief of Pediatrics) was sent to two mothers--one of these mothers soon dropped out because she felt her own son was not as handicapped as the other preschool children--who had been attending almost every meeting since September 1975.

By early December 1975, five or six mothers (all of whom had handicapped preschool children who required specialized programs) had established a pattern--they would meet every other Wednesday at 1:30 p.m. with the staff advisor present. This pattern persisted almost without interruption for one year. In October 1976, the parents began to meet in the evenings at the hospital because they thought more parents could find time to meet in the evening rather than in the afternoons. It was during this time period--late November and early December 1975--that the staff advisor began to encourage the mothers to create some structure so that they can do their work more efficiently; the staff advisor suggested three positions--"chairperson," "co-chairperson" and

"secretary." He emphasized the fact that the structure had to have the capacity to be flexible since the Association has relatively few participants. Three mothers volunteered after much discussion and with some apprehension as to whether or not they had the knowledge or experience to assume these positions. This basic structure of three positions has remained the same for more than one year. See Table 3 for the organizational chart of the Parents Association.

From November 1975 to January 1976, the parents met for a total of five meetings in the office of the Director of Community Relations, who was present at some of the meetings. Coffee and cookies were provided by the hospital. Some of the mothers brought along their children because they could not find, and in some instance could not afford, a babysitter. In early January 1976, Administrator A did not think she had to attend the meetings because she felt the parents were acting responsibly; and that the parents should locate another meeting place because the room the parents were meeting in was an <u>office</u> not a <u>conference</u> room. The staff advisor found another location for the meetings but the parents felt that ". . . we were

TABLE 3

ORGANIZATION CHART OF THE PARENTS ASSOCIATION

(AS OF JUNE 1976)

Staff Advisor

Executive Committee

Mrs. P. (Chairperson)	Mrs. J. (Co-Chairperson)	Mrs. T. (Secretary)	Mrs. F. (Fund Raising)

Non-Executive Committee Members

Mrs. C. (Fundraising)	Mrs. A.	Mrs. E.	Mrs. D.	Mrs. H.

Executive Committee's Responsibilities

1.	Taking minutes	Mrs. T.
2.	Reminding members of meetings	Mrs. T.
3.	Preparing agenda	Mrs. P.
4.*	Contacting hospital personnel, Community leaders	Mrs. P.
5.	Obtaining merchandise for flea market fundraising	Mrs. F.
6.	Planning organizational strategy with staff advisor	Mrs. C. Mrs. P.
7.	Recruitment of members	Staff Advisor

*Although other members had contacts with professional and administrative staff inside and outside of the hospital, it was the chairperson (Mrs. P) who took the initiative in this area.

pushed out because meeting in the office of the Director of Community Relations we were too visible to a lot of people and they probably did not want us to have all that publicity because other groups in the hospital would become jealous." The Director of Community Relations, though praising "militant" consumer activity, told the parents in no uncertain terms that (a) they should not expect the hospital to provide them with any resources for a specialized preschool program; and (b) it is not "advisable" for the parents to meet with the hospital's Community Board until the parents had something tangible to bring to the Board--in other words, not to approach the Community Board for any assistance.

The Role of the "Professional"

The demand that there should be more "citizen participation" (and less reliance on doctors, lawyers, social workers, etc.) for advice on 'what services are needed,' or 'how these services should be delivered' or 'who should be eligible for these services' has been argued on a number of different levels: (a) psychological --that people have a psychological need to participate

because such participation in the decision-making process gives them a sense of influence and control over their lives, that without such a sense of power, people begin to feel estranged from themselves as well as from others: (b) democratic ethos--that in a democracy--government by and for the people--citizens ought to participate in affairs which affect them either directly or indirectly; (c) practical--that only with constant feedback from citizens/consumers can social health/educational services be successfully designed in terms of its meeting an unmet need, program coverage, eligiblity, etc.; and, administrative--that citizen participation compels the bureaucracy to be more accountable and accessible to the public.

Whereas community control (citizen participation exerts complete control over professional activity) represents one end of the continuum, elitist planning (professionals exert complete control) represents the opposite end of the continuum. A case for elitist planning is made by Freeman and Jones:

> In these times it must be acknowledged that, in many ways, the expert is not only more available but better equipped and, on the average more likely to make advantageous decisions for the people he represents

> and sometimes for the entire community--than are the community members themselves. Contemporary history provides some glaring examples of erratic community behavior.[3]
>
> Rather than play the game of community involvement on every issue, it would be wiser to recognize the responsibility of professionals and to develop social control techniques that regulate their behavior and keep them in line.[4]

The debate over the correct form and proportion of citizen participation vis á vis professional involvement will probably never end since absolute answers are rare in the realm of human relations. What will be required are empirical examinations of different forms and proportions of citizen-professional participation for different situations. This project represents a case in point.

The staff advisor decided that he would act as a delivery agent for both the parents and the hospital in terms of helping both obtain a shared goal (viz., a specialized preschool program); however, the framework of normalization was utilized as a professional criterion to evaluate the appropriateness of any given decision. The staff advisor was not prepared to abdicate his allegiance to certain "professional" norms.

1. Recognizing that rational arguments in of themselves do not necessarily convince policy makers and

institutions to either modify or overhaul old programs or to implement new programs, the staff advisor's primary contribution to the Parents Association would be to facilitate an "encouraging environment" for the goals and activities of the parents within and outside of the hospital. The staff advisor's middle-management position within the hospital and his status (MSW) within the professional community gave him access to "key" persons and groups to whom he could "sell" the idea of a specialized preschool program. As Irving A. Spergel has stated, ". . . He [professional] must facilitate the flow of information about community problems to the community groups, and he must make certain that the role of the group is understood by the other significant sectors of the community."[5]

2. Another contribution the professional could make was the utilization of his technical knowledge to the maintenance and development of the Parents Association. E.g.: to help parents maintain a balance between structure, goals and allocation of resources so that they do not turn into--as many local community groups have a tendency to do--a social club and thereby forget their reason for

existence. To help "navigate" the parents within the maze of large organizations, departments, bureaus, divisions etc. so that they can learn for themselves how to reach the right person at the right time for the right resource.

Whereas the first contribution might be considered "salesmanship," the second "navigation," the third contribution may be considered "teaching." What will the staff advisor teach? First, specific administrative skills--e.g., how to chair a meeting, how to utilize minutes of meeting, how to speak to a bureaucrat when a request is made of him, etc. Secondly, to teach the "whys" and "hows" of certain strategies and tactics of accommodation, negotiation, or confrontation.

The staff advisor's plan, in accordance with a community development model, was to gradually become less involved (as "salesman," "navigator" and "teacher") as the parents became more confident and their Association more organizationally successful in achieving its objectives. It was expected that the staff advisor's involvement over a period of time would be most intense during the initial stage of planning and implementation and gradually less intense as the parents become more

accustomed to 'organizational work.'

There are, however, two qualifications to this estimated projection of professional involvement. First, that complete professional withdrawal or inactivity was not anticipated since his consultation and direct involvement might be required as the Association confronted either "crises" or complex technical matters (e.g., funding, grant proposals, etc.). Secondly, that though a community group, particularly in its "embryonic and fetal" stages of development, requires a heavy investment of professional activity, the staff advisor wanted the members of the Parents Association to be responsible for certain "tedious" tasks: e.g., taking minutes at a meeting, making phone calls, arranging schedules, etc. He wanted the Association to survive not on the basis of his professional involvement but on the basis of their own strong commitment to their association. As Harold Weisman astutely observed regarding the survival and effectiveness of neighborhood councils, ". . . it is possible that death comes to many councils because the commitment and the solidarity necessary to overcome major organizational problems never develop in the course of

dealing with minor problems. Workers take care of the minor problems simply because they are afraid the council might not survive otherwise."[6] The attitude of the staff advisor throughout the duration of the project was though he wanted to help the parents succeed he would not and could not take the responsibility for the survival of the Parents Association--if the parents themselves were not able, ready, or prepared to make a strong commitment to their own organization. See Fig. 2 for a visual representation of a hypothetical course of professional involvement over time--the vertical axis shows that it is at the beginning of program development ("initiation" and "contact")* that receives the most professional effort, that professional involvement gradually tapers off as the program becomes settled.

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*Every program moves through three stages of development. Initiation--involves procuring sanction, technological resources, community interest, etc. Contact--involves contacting potential program beneficaries. Implementation--is synonomous with the ultimate goals of the program, i.e., the program finally engages its clientele, gives services, and/or applies a change technology. See Social Program Evaluation by Tripodi, Fellin and Epstein.

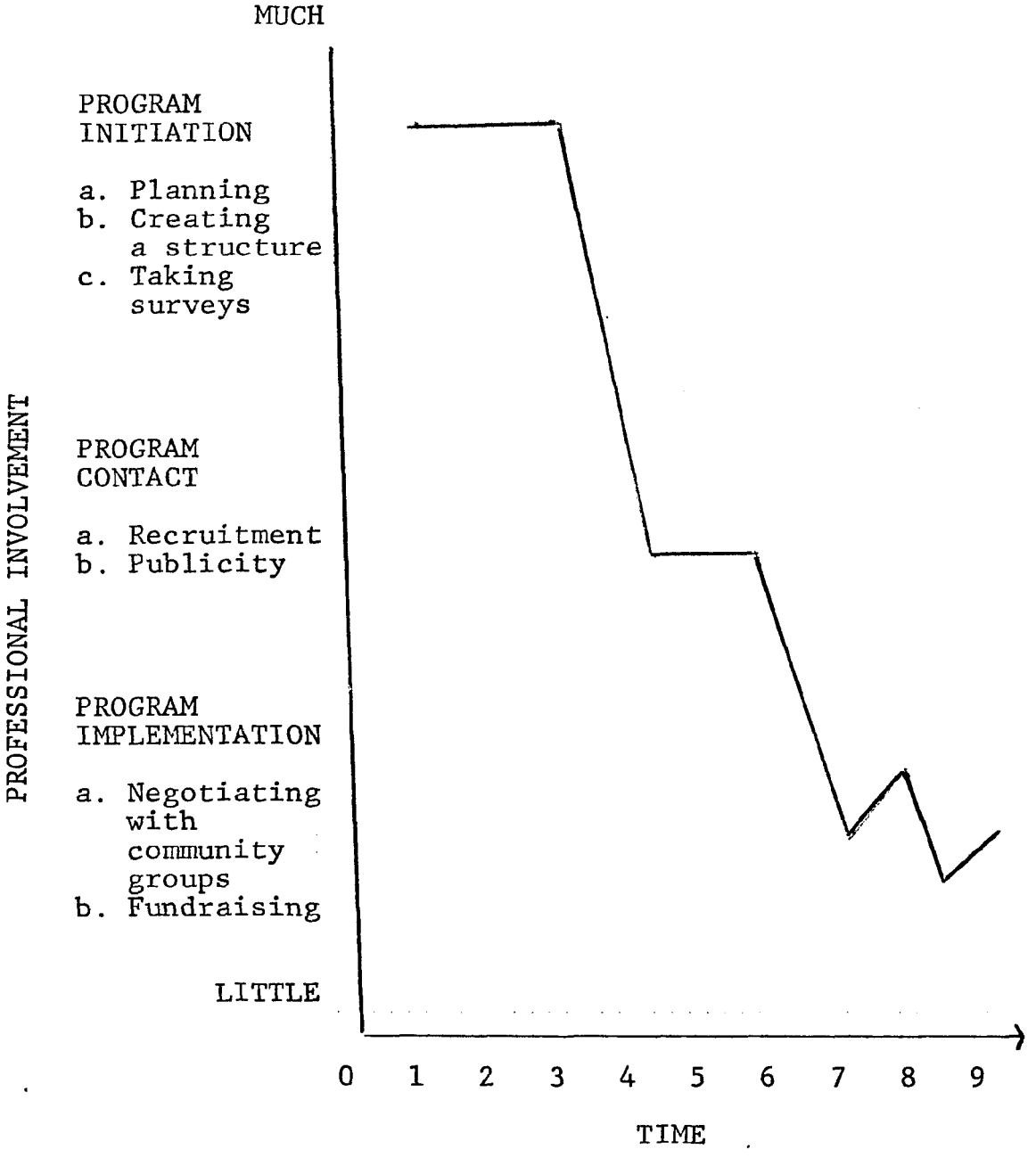

FIG. 2

HYPOTHETICAL COURSE OF PROFESSIONAL INVOLVEMENT WITH THE PARENTS ASSOCIATION OVER TIME

Anticipated and Unanticipated Consequences. It was anticipated that the staff advisor would experience some role strain as he tried to balance the variety of demands made on him by the parents, by various hospital personnel, as well as by his own commitment to certain professional norms. Although he considered himself an advocate--some might say a "zealot"--for the handicapped children and their families--he was not prepared to either become an "agency insurgent" (i.e., identifying completely with the parents) or an "organization functionary" (i.e., identifying completely with the hospital).

It is axiomatic, sociologically, that individuals will utilize a variety of mechanisms to reduce role strain. In his analysis of role strain, William J. Goode concludes: "The individual's problem is how to make his whole role system manageable, that is, how to allocate his energies and skills so as to reduce role strain to some bearable proportions."[7] The staff advisor recognized that although the parents and hospital shared a common goal--i.e., obtaining a specialized preschool program--there might be honest differences as to how this shared goal can be

operationalized. It was anticipated that the staff advisor might be forced to become more of a "mediator" (i.e., bringing different parties together) rather than an advocate (i.e., taking a stand on any given issue) if and when the situation did not reflect a high degree of consensus. One of the evaluation questions for this project was: Did the staff advisor experience role strain? and how did he attempt to reduce it? Describing a comparable situation where professionals had to represent an organization as well as a group of consumers of social services, Neil Gilbert concluded, ". . . most coordinators respond to both agency and citizen interests, and in doing so walk the tight rope between advocate and middleman. To maintain this balance, they become masters at negotiation, accommodation, and manipulation of citizens and agency staff."[8]

Practice Principles and Hypotheses

The Parents Association can be conceptualized as an intervention set--a series of interventions to effectuate a change: in this particular instance, the creation of a needed community service for developmentally

handicapped children. We might also add that this intervention set was varied rather than fixed. This project included at a minimum the following interventions:

(a) the staff advisor working with the PA at their scheduled meetings

(b) the staff advisor working with the chairperson only

(c) the chairperson working with other members of the PA

(d) the chairperson working with community groups and agency personnel

(e) the staff advisor working with community groups and agency personnel.

This was considered a varied set of interventions because the staff advisor's objective was not to keep any independent variable constant so that he may study its effects but to achieve change for the target population (handicapped children and their families). To quote Edwin J. Thomas "The objective of research is to evaluate the effects of one or more independent variables, whereas the objective of practice is to achieve change in given target behaviors."[9]

The project was designed to consider six hypotheses:

1. That a hospital-based Parents Association with professional assistance can be created and implanted in the hospital;

2. That a PA can be successful in reaching its objectives though the Association may be small in numbers (10 to 20 parents);

3. That a PA would generate intense parent participation if the members were working for a program that would bring direct, tangible benefits to their own handicapped children;

4. That a PA as an auxiliary group would rely relatively more on collaboration and negotiation rather than on contact and conflict to obtain its objectives;

5. That the parents of the Association would be accepted into the hospital's decision making process and thereby become "institutionalized" into the hospital system, i.e., parents would be allowed to engage in routine interaction with other hospital units. That the degree of institutionalization within the hospital would be contingent upon the amount of power and influence the PA

possessed.

6. That the staff advisor would experience conflicting demands made by the parents, the hospital and the community and he would be forced to utilize mechanisms to reduce the role strain. For example: he might have to play more of a mediating role to reduce the role strain.

Whereas hypotheses specify what is expected to happen based on theoretical considerations, practice principles provide the practitioner with guidelines for action. The project was designed to incorporate the following practice principles and rules:

1. The parents should be encouraged to take the initiative in implementing their own decisions as much as possible and as far as possible: so each parent can learn to become resourceful, confident, and feel a sense of commitment to the association.

Rule 1. The staff advisor will not do what the parents can do for themselves--e.g., phone calls, scheduling meetings, etc., unless the parents lack either a particular skill or confidence to carry out a specific task.

2. In a pluralistic society, the allocation of resources is often determined through a negotiation/accommodation process which involves parties with vested

interests. Parents as consumers should actively participate in the process so that they can learn how to become effective community leaders, which in turn would increase the effectiveness of their association.

Rule 2. The staff advisor will encourage the parents to participate at community meetings, panel discussions . . . to encourage professional and administrative staff within and outside of the hospital to include the parents in decision-making discussions which pertain to handicapped children.

3. Parents are to be viewed as volunteers, who should receive recognition and status as both an incentive and reward for their service to the community. Experience has shown that unless this recognition is given volunteers often decide not to continue volunteering.

Rule 3. Wherever possible the parents are to receive letters of commendation from the hospital's administration or to sponsor ceremonies or festivities which publicly praise their community efforts.

4. The staff advisor will adhere to the normalization principle--i.e., the utilization of means which are culturally normative as possible, in order to establish

and/or maintain personal behavior and characteristics which are culturally normative as possible.

Rule 4. To encourage parents to promote the normative principle--e.g., to use a school rather than a hospital for the preschool program since formal learning takes place in schools not in hospitals; or, to make certain that the retarded child is not segregated from normal children in any setting.

The Evaluation Component

The Parents Association had two purposes--one primary and one secondary. The primary purpose was the creation, with the assistance of a professional staff member, of a Parents Association whose ultimate goal was to obtain the creation of a specialized preschool program. The secondary purpose was to implant a consumer group within the hospital system.

As an applied-research project, the evaluation component was not only concerned with effect detection, that is, to what extent did the Parents Association achieve its objectives--e.g., acquire resources such as funds, equipment, space, community/hospital support, etc.?

But it also included the careful specification of program inputs, of participants, and of environmental conditions so that we can begin to explain which factors are associated with successful or unsuccessful outcomes. Based on the assumption that methodology must flow from the problem, the case-study approach (with the staff advisor as observing-participant) was utilized. It is interesting to note that in his appraisal of twenty-five years of social problem research, Melvin L. Kohn recommends that more research is needed which ". . . make explicit the assumptions underlying current and proposed social policies and to analyze these assumptions empirically" and that ". . . participant observation more than quantitative data can eliminate fundamentally erroneous assumptions."[10] Since the focus was on what changes were produced in terms of task and process objectives, the analysis will require a visual inspection of the data to determine whether a practical difference resulted from the intervention(s)."

Using George W. Fairweather's framework for the evaluation of social innovations, the following categories will be described and assessed:[12]

A. Outcome Criterion--to what extent did the parents achieve their objectives (e.g., obtaining funds, community support, equipment, etc.). A daily planner was used to record and document the nature and range of the efforts and achievements made by the staff advisor and the parents.

B. Participant Characteristics--Sex, age, educational background, personality characteristics, organizational affiliations, marital status, and socioeconomic status. Informal interviews, and administrative records were utilized to obtain these characteristics.

C. Social Situation Variables--the situation in which the Parents Association was operative.

To use Fairweather's equation, the outcome (achievements of the Parents Association; its integration within the hospital) was a function of the participants (attributes of the parents such as education, age, expectancies, etc.) and the social situation (the Parent Association's internal processes such as its economics, social structure and group dynamics; and the external processes such as publicity, state of the economy, relationship to other community institutions, etc.)[13]

Internal Processes	External Processes
Suggestions and comments on Parents Association by members (informal interviews, observations)	Suggestions and comments on social subsystem made by others (informal interviews, observations)
The structure of the organization; type of work performed; types of discussions (informal interviews, observation and recording forms)	State of the economy; social climate of the hospital in which project is implanted (newspapers, observation, administrative records)
Fiscal processes (administrative records)	Narrative account of events related to external processes (research journal)
Narrative account of events related to internal processes (research journal)	

In summary: a daily planner, a recording form for Parent Association meetings, informal interviews, observation, research journal (anecdotal material) administrative and clinical records, and newspaper articles were utilized to measure internal and external processes. The staff advisor had planned to periodically administer some standardized tests to the parents to determine if their feelings regarding their ability to effectuate change had changed. Two brief questionnaires were administered at a scheduled Parents Association meeting in March 1976 (see

Appendices D and E). Up until that date the staff advisor had not indicated to the parents that he was using the PA as an applied-research project. He had been concerned that the hospital administration might want to find an excuse to use perhaps at a later date when controversy might erupt, to discredit both the parents and/or the staff advisor; and that an administrator might "suggest" that the staff advisor was "more" concerned about his doctoral research than the interests of the children and their parents.

As soon as the staff advisor informed (as the result of his ethical responsibility as a researcher) the parents that he was "using" their association as an object of study because he was interested in doing research about self-help groups, he asked them to complete two forms--which took no more than fifteen minutes to complete. Most of the parents expressed eagerness to assist the staff advisor in his research efforts. As one mother put it, "You had been helping us to get something for our children, I'm glad we now have the chance to help you. . . ." It was a day or two after the meeting that the staff advisor began to get negative feedback--at least four parents felt

embarrassed that they were not members of any organization (the staff advisor made the mistake of asking them to put their names on the completed forms), and one parent called in panic because she said that she did not want to reveal any of her political viewpoints.

In retrospect, the staff advisor's mistake was to inform the parents at a relatively late date that he had a "research interest" in their activities; consequently, they reacted with anxiety and apprehension to the brief forms he had asked them to complete. After that incident, the staff advisor never gave them another questionnaire to complete--since he did not want to create an additional source of anxiety for individuals who already had so many problems to shoulder; nor did he want his own presence as a researcher to generate results which would represent an artifact of the program.

In March 1976, the staff advisor received permission from the parents to use a tape recorder at their meetings. He explained that it could be helpful to him for "research purposes," and that it could also assist them in listening to how they in fact conduct meetings. The staff advisor as well as the parents agreed that the

recorder was inhibiting discussion--either the staff advisor or the parents would frequently request that the recorder be stopped so that they can say something that was "controversial" or "sensitive." Thereafter the tape recorder was never used again. (In November 1976, the chairperson asked the staff advisor what had happened to the tapes. She was "curious" whether any university faculty member or student listened to the tapes because she wanted to know how others might interpret what they had heard.)

Assessment Devices

1. Informal interviews rather than structured or focused interviews were utilized because the staff advisor felt that informal interviews would be perceived by the participants as a "natural occurrence," i.e., just a friendly talk with the staff advisor, rather than an "artificial" act.

The staff advisor had hoped he would be able to informally interview parents and significant hospital personnel at various points in time to determine if their views had changed over time. But such systematic interviewing was not always possible since parents were not

always available to the staff advisor for interviewing--their children were sick for one or two weeks or family problems or visits to other agencies prevented the mothers from keeping their clinic appointments.

Since the staff advisor was in a middle-management position, he was not always in a position to informally interview a Chief of Service or an Administrator unless the staff advisor had a specific reason for requesting such a meeting: which meant that he could not always speak to a particular administrator every two months to obtain certain data. And the staff advisor did not want to "fabricate" reasons for meetings because then his behavior would be an object of suspicion and distrust.

2a. The Daily Planner (see Appendix B for typical entries for three different days in three different months) was devised to capture the range and nature of activities that the parents and staff advisor were involved with. The staff advisor attempted to fill out the daily planner before the end of each working day (5:00 p.m.) as a means to minimize failure of recollection. In addition, he tried to record only facts rather than an interpretation of the facts unless the interpretation of a fact was given to him by a parent, hospital administrator, community leader, etc.

By staying with only the description of the situation the staff advisor attempted to minimize his own "distorted" preception--although an "immaculate" preception is an impossibility.

2b. Record of Meetings (see Appendix C). This form was utilized to record the discussions and decisions of the Parent Association meetings in an organized and systematic manner. It was adopted in its entirety from William W. Biddle, The Community Development Process: The Rediscovery of Local Initiative (New York: Holt, Rinehart and Winston, Inc., 1965).

3. Administrative and economic records have been traditionally utilized to measure dimensions that pertain to participatns and the social situations. The staff advisor had to choose items which were relevant to his project. For example, the table of organization for the Parents Association and the hospital were important administrative records. Clinical material (e.g., intake interviews) was also considered an administrative record.

The staff advisor attempted to increase reliability by checking as many different records (and through informal interviews) to determine whether information on any given item was accurate and reliable.

4. Sociometric scales administered were taken from the Handbook of Research Design and Social Measurement (second edition) by Delbert C. Miller (New York: David McKay Company, Inc., 1970). The advantage of using scales already tested was that the test's validity and reliability had been rigorously established. (See Appendices D and E.)

5. Research Journal--applied to all dimensions of the project. It was a description of the "life" of the project. It was also a method to describe "critical incidents," particularly incidents that occurred only once. (Material recorded in a research journal is rarely used to produce formally scored items but may be categorized by frequency count or nature of content.) (See Table 4 for the General Plan of the Project.)

TABLE 4

GENERAL PLAN OF THE PROJECT

Program Phase	Time Scale	Evaluation Activity
Planning	Minus 4 months 5/75 Minus 3 months 6/75 Minus 2 months 7/75	Modification and perfection of assessment devices
	Minus 1 month 8/75	Utilization of research journal
Initiate Sub-Systems (Parents Association)	0 months 9/75	'Take off' period for project
	Plus 3 months 12/75	Use of research journal and participant observation
Action	Plus 4 months 1/76 Plus 5 months 2/76 Plus 6 months 3/76 Plus 7 months 4/76 Plus 8 months 5/76 Plus 9 months 6/76	Use of daily planner Informal interviews Administer sociometric scales Use of tape recorder at parent meetings
Close Sub-System (For Evaluation Purposes Only)	Plus 12 months 9/76	Record 'critical' incidents (e.g., teacher removed from program; WABC TV and newspaper publicity) Dissemination and publication of evaluation for university

Notes

1. Jon Nordheimer, "Citizen Role in Government Emerges as Theme of California's Gov. Brown," New York Times, 23 February 1977, p. A10.

2. David Vidal, "The P.T.A. Is Not What It Was--Happily, Some Say," New York Times, 12 December 1976, sec. 4.

3. Howard E. Freeman and Wyatt C. Jones, Social Problems: Causes and Controls (Chicago: Rand McNally and Company, 1971), p. 226.

4. Ibid., p. 228.

5. Irving A. Spergel, "Organizing the Local Community: The Social-Stability Approach," Strategies of Community Organization: A Book of Readings, 2d ed., edited by Fred M. Cox, et al. (Illinois: F. E. Peacock Publishers, Inc., 1974), p. 271.

6. Harold H. Weissman, Community Councils and Community Control: The Workings of Democratic Mythology (Pittsburgh: University of Pittsburgh Press, 1970), p. 87.

7. William J. Goode, ed., The Dynamics of Modern Society (New York: Atherton Press, 1966), p. 10.

8. Neil Gilbert, Clients or Constituents (San Francisco: Jossey-Bass, Inc., 1970), p. 89.

9. Edwin J. Thomas, "Uses of Research Methods in Interpersonal Practice," Social Work Research: Methods for the Helping Professions, rev. ed., edited by Norman A. Polansky (Chicago: The University of Chicago Press, 1975), p. 268.

10. Ibid., p. 279.

11. Melvin L. Kohn, "Looking Back--A 25-Year Review and Appraisal of Social Problems Research," Social Problems 24 (October 1976): 104-105.

12. George W. Fairweather, Methods For Experimental Social Innovation (New York: John Wiley and Sons, Inc., 1968), pp. 77-93.

13. Ibid., pp. 98-107.

CHAPTER V

DESCRIPTION OF THE PARENTS ASSOCIATION

Introduction

Since the outcome of this or any innovative project is a function of the participants involved and the social situation (internal and external processes) in which the project is embedded, this chapter will describe (a) the characteristics of the parents who actively participated from January 1976 to June 1976; and (b) the social situation covering the same time period.

As a service project, the Parents Association possessed the following characteristics:

> It [service project] defines a significant problem, makes naturalistic observations, creates one new social subsystem and implants it in the appropriate social setting, is longitudinal in time, assumes responsibility for lives and welfare of the members participating in it, and uses a multidisciplinary approach. It does not create different sub-systems as alternative solutions to the social problem and, hence, does not design experiments to compare these created solutions.[1]

If we can accumulate case-studies of community participation,

we might eventually discern the significant variables. According to Ray Lees, "action research in community programs offers the opportunity to build a collection of 'public administration cases' analagous to the business cases used in teaching at Harvard and other business schools."[2] Ray Lees concludes ". . . it is important to have on record how decisions are made: how much information is necessary, who influences the outcome the most, how disagreements are resolved, what procedures are used and in particular what is the effect of community initiatives on the way choices are made."[3]

Some projects may involve low-income participants but aspects of the social situation may be different (e.g., community agency vs private voluntary agency); or the social situation can be equivalent but the participants may vary (parents vs nonparents or married vs single). The ultimate goal of such a catalog of case studies on community participation is to determine what variables are either necessary or sufficient or both to the outcome.* We may then

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*See Hubert M. Bladock in his Causal Inferences in Nonexperimental Research (Chapel Hill: University of North Carolina Press, 1964) refers to Stefan Nowak's description of the various combinations of how condition A may be

be in a position to stipulate with some degree of accuracy a specific design for a specific outcome--which is the ultimate goal of program evaluation.

Participants

Who in fact participated? Was it a homogeneous or heterogeneous group in terms of age, marital status, ethnicity, educational background, etc.? The background material was obtained from the Developmental Center's intake studies--which usually included certain baseline data on each family that seeks assistance from the Center. Table 5 gives the basic background data of the "nucleus"

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related to condition B.

1. A is both a necessary and sufficient condition for B.
2. A is a necessary but not a sufficient condition for B (i.e., A must be present, but B not always follows A).
3. A is a sufficient but not a necessary condition for B (i.e., B is always present when A is, but B may also occur when A is not present).
4. A is only partly necessary and/or sufficient for B (i.e., A must usually be present for B to occur, etc.), p. 31.

TABLE 5

BACKGROUND CHARACTERISTICS OF PARTICIPANTS

(AGE, LAST SCHOOL GRADE COMPLETED,

ETHNICITY, MARITAL STATUS)

Name	Age[a]	School Grade	Ethnicity	Martial Status
Mrs. P. (Chairperson)	39	High School Equivalency Diploma	Irish	Married
Mrs. T. (Secretary)	26	12th	Italian	Married
Mrs. J. (Co-Chairperson)	26	12th	Black	Married
Mrs. E.*	28	10th	Jewish	Married
Mrs. F.	40	11th	Italian	Married
Mrs. H.	42	12th	Irish	Married
Mrs. C.	27	11th	Hispanic	Married (common law)
Mrs. A.	30	12th	Jewish	Married

[a] Average age = 32 years Median age = 28.5 years

*Mrs. E. stopped participating in May 1976. The staff advisor could not reach her by phone nor did his letters get answered. Once the staff advisor asked the chairperson if she had any "guess" as to what happened to Mrs. E. In a hesitating voice, Mrs. P. thought it might be related to an incident where Mrs. E.'s feelings were "hurt" by another parent. Further probing could not get Mrs. P. to be more specific--as if she did not want to say more!

participants--i.e., those who attended at least 75% of the total number of the scheduled meetings and who were also involved in the Association's fund raising projects or had attended ad hoc community meetings.*

Although this was a small group, it was both homogeneous in terms of age, educational background, marital status, but heterogeneous in terms of ethnicity. After June 1976, another Black mother (high school graduate) and another Jewish mother (college graduate) joined the Association.

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*Excluded from Table 5 is a Hassidic woman (age 26) and a Spanish-speaking woman (age 24). Both attended meetings but less than 75% and neither became involved in any of the Association's fund raising projects. The Hassidic mother had three children, two of whom were moderately to severely retarded; she found it difficult to attend the meetings because (a) no babysitter, (b) travelling problems--she lived outside of the hospital's catchment area and had to use three buses which was physically exhausting or use car service which was financially prohibitive.

The Hispanic mother, who had a profoundly retarded child who was wheelchair-bound, came consistently until she, too, moved outside of the catchment area.

We can conclude that geographical proximity to the hospital was a necessary but not sufficient condition for participation.

The group was also homogeneous in terms of socio-economic status--the majority either collected public assistance (AFDC) or Medicaid. See Table 6 for the individual breakdown of source of income.

Out of the eight participants, six received some income subsidy from a governmental program. We might also add that all the participants were alike in that they all had to cope with disabled, and in two cases multihandicapped, children. Many of the families had to cope with stresses over and beyond the care and management of a disabled child:

1. The chairperson's husband was not working because he had a recent mental breakdown. He was stabilized on psychotropic medication.

2. The secretary had to cope with a crowded living situation--a family of five living in three small rooms. She could not afford to pay a higher rent for a larger apartment. In addition, her husband who has three daughters from a previous marriage was having serious "court battles" with his ex-wife.

3. Mrs. F. who has four children living at home was forced to move to another apartment because she had to

TABLE 6

ECONOMIC STATUS OF PARTICIPANTS

Name	Source of Income
Mrs. P. (Chairperson)	Mother worked full time; Medicaid; Husband was unemployed.
Mrs. T. (Secretary)	Husband unemployed; Medicaid benefits.
Mrs. J. (Co-Chairperson)	Husband unemployed; AFDC.
Mrs. E.	Unemployment and Medicaid benefits.
Mrs. F.	Unemployment benefits; husband refused to apply for Welfare or Medicaid.
Mrs. H.	Husband works full time. Child's multiple disabilities made him eligible into programs without a fee.
Mrs. C.	AFDC.
Mrs. A.	Husband worked full time.

find a "cheaper" apartment.

4. Mrs. C. had to cope with an alcoholic husband as well as a profoundly retarded daughter and three other children (one of whom with a history of hospitalizations for seizures.)

Community Participation

On the average the participants scored very low on 'community involvement.' The scores were obtained by having each parent complete Chapin's Social Participation Scale (see Appendix D). A high score of 18 and over represents "titular leader achievement."[4] A "0" score indicates that the parent was not affiliated with any organization except for the Parens Association. See Table 7 for the individual's scores.

What is evident was that the parents who were involved extensively as well as intensively in the Parents Association had a previous history of either minimal or no community participation. The chairperson, however, had a high score. Since that score (37) was based on the chairperson's organizational affiliations prior to her joining the Parents Association, we can not attribute her current

TABLE 7

PARTICIPANTS' DEGREE OF

COMMUNITY INVOLVEMENT

Name	Score
Mrs. P. (Chairperson)	37
Mrs. T. (Secretary)	0
Mrs. J. (Co-Chairperson)	0
Mrs. E.	0
Mrs. F.	0
Mrs. H.	30
Mrs. C.	6
Mrs. A.	0

interest in community affairs to her participation in the Parents Association.

Two parents, Mrs. T. and Mrs. C. reported that they had participated in an ad hoc protest school meeting in September 1976 when the schools their children attended were subject to severe budgetary cuts.

Costs of Participation

Many of the parents who actively participated had to face the "consequences" either at home or in the office. Mrs. T., who had never joined or participated in an organization, had "fights" with her husband for the first two or three months because he was forced to stay home and babysit so his wife could come to the meetings:

> Mrs. T.: "I told him its not only for my satisfaction that I was coming--it was for the health of his daughter--but certainly I enjoy leaving the apartment to meet with other adults. He has a good thing going so I'm not afraid of his bark though I sometimes get tired of his complaining."

Because the chairperson worked full-time (15 minutes away from the hospital by care), she had to leave work to attend the afternoon scheduled meetings; but she had to make-up the hours away from employment. When her "old"

boss left and she had to be accountable to a new boss, she worked under severe strain:

> Mrs. P.: "I don't know what I'm going to do. I don't want to get fired but yet I want to participate. My only chance is to educate this new boss and make myself indispensable at work."

Mrs. C. reported that every time she left for a meeting her husband harrassed her for leaving him. Mrs. C. came to the following conclusion:

> Mrs. C.: "My husband acts up every time I come to the meetings because he hates to admit that his daughter is retarded. When I come to the hospital for any reason, he can't face the fact that I'm going because his daughter has serious multiple disabilities."

Another characteristic of the group was that all the participants had a strong "feeling" that they could exert some control over their own destinies. This "feeling" was ascertained by having each participant complete Neal and Seeman Scale of Powerlessness (see Appendix E). A low score indicates that the individual feels a sense of "mastery" whereas a high score reveals a sense of "powerlessness." See Table 8 for the individual scores. It should be noted that the test was administered on March 17, 1976--a week before the hospital received a letter from the Board of Education confirming the fact that they

were interested in providing the hospital with a Special Education Teacher--but three weeks after the Assistant Director of BCRMD announced at a meeting that her Bureau will give the parents a teacher; the parents completed this (self-administered) test after they had succeeded in getting the Board of Education to make a commitment to support their program.

TABLE 8

PARENT SCORES ON THE NEAL AND SEEMAN POWERLESSNESS SCALE

Name	Score
Mrs. P. (Chairperson)	0
Mrs. T. (Secretary)	2
Mrs. E.	2
Mrs. F.	2
Mrs. H.	0
Mrs. C.	1

The lowest possible score is "0" and the highest possible score is "14."

Social Situation Variables

Background

On April 20, 1976 Administrator E* and the Director of the Board of Education Bureau For Children With Retarded Mental Development signed a letter of agreement which stipulated what each institution would provide to establish a specialized preschool program. He requested that the letter be drafted by the Staff Advisor. The following are excerpts from this letter of agreement:

> . . . We are delighted that the Board of Education and our hospital are to co-sponsor a most needed community project for preschool children who are retarded and developmentally disabled. Our mutual goal in this project is to prepare these children intellectually, emotionally, and socially for entrance into the public school system.
>
> This Project is indeed a "community project" since it is a direct outgrowth of our hospital's Parents Association efforts to obtain more services for handicapped children. . . .

The parents had a sense of disbelief that a letter of agreement was actually signed. They were elated but

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*Letters have been substituted for names so that an individual's identity can remain anonymous. What is important for this study is the behavior and attitude of a given actor rather than his/her title or position.

could not really believe that their ultimate goal of obtaining a preschool program had become a reality in such a short period of time (from January 1976 to April 20, 1976). The staff advisor was also surprised since his expectation was that the program would be obtained no earlier than September 1976. The hospital agreed to provide suitable space for about 5 to 10 handicapped children (ages 3 to 5) who were registered with the Development Center; to provide meidcal, psychological and social services which were routinely provided by the Developmental Center; to recruit volunteers so that the program could maintain a suitable ratio of adults to children. The Board of Education agreed to provide a licensed special education teacher; to provide $400 per class for equipment (which also included tables and chairs).*

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*The special Education Teacher as well as the $400 per/class were financed through Title VI-B funds. In informal conversations, the Board of Education informed the parents and the hospital that they were in a "hurry" to give the hospital this teacher in April 1976 so that they wouldn't lose the "line" for September 1976. In addition, they told the parents that there was a good chance of getting two teachers and a paraprofessional in September 1976.

Initially, the parents as well as the staff advisor had recommended that the preschool program be located within a neighborhood public school so that the children can be viewed as students rather than patients. It was the Board of Education* which wanted the hospital as the site for the program based on the following considerations:

(a) public schools have many architectural barriers which could prevent children in wheelchairs from participating;

(b) principals often do not understand the needs of children with special problems;

(c) the special education teacher would feel more secure if s/he had close contact with clinical personnel

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*Before the Bureau of Children For Retarded Mental Development (BCRMD) agreed to provide the hospital with a teacher, the parents and the staff advisor had met with members of the District School Board. The School Board wanted to consider using an "underutilized" school building for the preschool program: if a school remained underutilized it was in danger of being closed due to budgetary cutbacks.

In late May 1976, after the teacher had already been assigned to the hospital, the School Board requested a meeting with the staff advisor and the parents to discuss "why" the program had not been located in a public school building. The parents convinced the School Board that the children were too 'medically involved' for a school setting.

such as physicians, physical therapists, etc., since many of the children would be multiple handicapped.

The Bleak Economic Environment

The success of the Parents Association in establishing a preschool program borders on the "miraculous" when we consider that 1975-1976 was the time that New York City was ready to go "bankrupt" and all municipal services, including police and firefighting services, were retrenched --i.e., employees were laid-off. In 1975, the hospital, like many other municipal hospitals, had to lay-off clinical and laboratory staff; and in some instances, physicians who were part-time were either not rehired or had their hours reduced.

For the municipal hospital system there was not only retrenchment but closing of at least two hospitals as well as rumors that the City no longer wanted to support the municipal hospital system (Health and Hospital Corporation) because a dual hospital system--public and private--was too expensive for the City to maintain. Some political commentators have attributed President Ford's defeat in the November 1976 election to the fact that the majority of New York City residents were outraged that his administration

did nothing to save the programs which were being phased out to balance the City's budget.

The severe budgetary problems of the City (external processes) had both a positive as well as a negative impact on the efforts of the Parents Association: (1) The District Board was interested in the preschool program because it wanted to "save" an underutilized building (if it were closed, teachers would be laid-off); (2) The Bureau of CRMD wanted to save federal "lines" (i.e., monies for teaching staff) for September 1976 so they were delighted that the Parents Association had pressured for a preschool program; (3) The hospital was able to provide space because they had closed wards due to budgetary cutbacks (no money to hire nursing staff).

In early September 1976, the Board of Education had to remove the special education teacher from the preschool program because the Board could no longer afford to support a legally non-mandated program. The following are excerpts from Chancellor Irving Anker's letter (dated Dec. 9, 1976) to the staff advisor:

> This letter is in response to your request, on behalf of the parents and staff of . . . for assistance which would bring about the formal restoration of a preschool

program for children.

> The inadequate dollar allotment were received necessitated our reaching the unhappy decision to transfer the funds previously used for preschool children to our Early Education section where the Board of Education has the legal responsibility to provide adequate services for handicapped children.

Lack of funds was a problem even before the Board of Education made its decision to remove the teacher in September 1976. Although the hospital agreed to provide space for the program, the hospital administration told the parents that they--the parents--might to have to "clean" the classroom because of the severe manpower shortage in the housekeeping staff. In May 1976, Administrator B told the staff advisor that the Executive Director "was not happy" with the fact that no one was paying the hospital for the "use" of the classroom.* For the hospital, money was always a primary consideration. The following is an excerpt from the memo (dated April 14, 1976) Administrator

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*The staff advisor responded by saying that he was sure the parents would be willing to pay part of the cost for the use of the classroom. The Administrator became visibly upset and acknowledged that it would be "criminal" to take money from parents of "handicapped" children.

B sent to the Executive Director when it became clear that the Board of Education was ready to staff the preschool program:*

> The advantages of this joint school program to the children, parents and our . . . Development Unit and the hospital are self-evident. In the case of the latter, two additional out-patient visits will be generated as consultations are provided and patient activity in program stimulated.

Social Climate

The social climate of the Parents Association represented the degree to which various hospital personnel accepted the Association as a legitimate subunit. Informal interviews were used to gauge the perception of significant

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*The staff advisor did not see this memo at the time it was written. Only after Administrator B was ready to leave the hospital in November 1976 to assume a new position at another hospital, did the staff advisor ask the Administrator for a copy of the memorandum.

At the time Administrator B sent this memorandum he described the staff advisor as a "sergeant" who was advancing while the army was retreating. His army metaphor implied that it is no easy task to push for new programs at a time when the survival of established services are at stake.

hospital personnel of the parent's efforts to establish a preschool program.

1. Administrator A--There was a discrepancy between his rhetoric and his actual instructions to the parents and the staff advisor. At the first two or three meetings in September 1975 he spoke about the need for "organized and militant consumer action" but at the fifth meeting instructed the parents not to request assistance from the Community Board.*

In April 1975, when the parents wanted to enlist his support in getting the hospital to locate the program on the third floor near the Developmental Center, he refused to take a stand.

In January 1977, when the parents put on the pressure for the hospital to submit a federal grant (demonstration preschool program), Administrator A resented the

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*Each hospital of the New York City Health and Hospitals Corporation must have an advisory Community Board. "Functions in which Community Boards shall participate will include, but not be limited to, the following . . . establishing of priorities . . . allocation of funds . . . area-wide planning . . . acceptability of services," from Interim Policy and Guidelines: The Community Boards of the New York City Health and Hospitals Corporation.

idea that the Executive Director assigned him the job (without reducing his regular assignment) of "getting the grant out." At one meeting he raised his voice and with a note of irritation said, "You better not sic the parents on me. I'm not getting paid extra to do this." He also acknowledged--at another meeting--that "Mrs. P. has proven herself to be an effective consumer advocate."

The attitude of Administrator A was of acceptance of the Parents Association as a legitimate and necessary voice within the hospital; however, when the situation got "hot," his willingness to act in behalf of the parents--even when he recognized that the parents had a powerful case--became strained. We might infer from his actions that his primary allegiance was always to the Executive Director.

2. Administrator B--The staff advisor had very limited contact with the Administrator until the staff advisor began working with the Parents Association. When Mrs. P. called the Administrator two or three times in May 1976, he responded quickly to her requests and his attitude was that of acceptance.

When in late November 1976, the Administrator left

the hospital, the staff advisor asked for a meeting to get the Administrator's perception of the Parents Association. He did not respond specifically to the questions, "How did you feel about the parents' involvement in obtaining the preschool program? Did you feel that they have acted responsibly?" Instead, he said that whatever "we" do should go through "affiliation channels" before it goes to the Executive Director.

Administrator B gave the impression that he 'cared' about the programmatic needs of handicapped children and that he did not question the parents right to become involved.

3. Administrator C--He was the person to whom the staff advisor was directly accountable for administrative matters. He expressed annoyance and, at times, disdain whenever the staff advisor mentioned the Parents Association or whenever he received a call from Mrs. P. He said on at least three occasions: (a) "Parents should not dictate policy to professionals"; (b) "If parents sit down with professionals at a meeting then professionals cannot talk honestly"; (c) "Mrs. P. sounds like she read a book on how to make people feel guilty"; (d) "If it was any

other lay person I would give her the 'back of my hand' but I was specially tolerant of Mrs. P. because I know that these mothers of handicapped children are emotional people"; and, (e) "That I hold you, the staff advisor, responsible for the actions of the parents."

From the months of January to June 1976, he viewed the parents' involvement as a nuisance and a great source of irritation; however, he never questioned the right of the parents to organize into a Parents Association.

4. Administrator D--She gave encouragement to Mrs. P. as well as to the other parents to remain organized. She felt that Administrator E was a "paranoid autocrat" who had to be kept in check by community people who had no "ax to grind." At the Community Board meeting on September 20, 1976, at which time Mrs. P. and the other parents were invited to report on this program, the President of the Auxiliary announced how the parents accomplished so much in such a short period of time: and that 'what' they were fighting for was so much needed in the community.

Administrator D (who has given service to the hospital for the past eighteen years) seemed genuinely sincere about her support for the Parents Association.

She saw the parents as a source of countervailing power against what she considered an inept and power-hungry administration.

5. Administrator E--The staff advisor never had an opportunity to ask him directly what he thought of the parents' efforts inside and outside of the hospital. The day he put his signature on a publicity flier which the parents wanted to distribute throughout the hospital was the only written approval the Association received from the Administration. He never questioned the use of the phrase Parents Association in the letter of agreement between the hospital and the Board of Education. In December 1976, he issued a brief news release to the local newspapers: which stated that the hospital's preschool program was sponsored by the Parents Association.

Administrator C warned the staff advisor not to be naive about Administrator E's motives: "Sure he's talking nice to Mrs. P. and he gave the parents a room on a closed ward. His credibility with the community is at its lowest ebb since the budget cuts. And the parents offered him a ready-made free program which he can take credit for." This viewpoint was partially collaborated when in

April 1976 the parents asked Administrator A, "Now the Board of Education gave us a teacher, how should we thank the Executive Director, with a personal visit to his office? or a letter? (The staff advisor suggested this approach to the parents because he felt that the Administration had to get the message that the parents understood the principle of exchange.) The Executive Director said he preferred a letter since he was too busy to meet with the parents--but the tone of Administrator A suggested that he wanted the letter for public display at his meetings with the Community Board.

6. Administrator F--The parents had no contact with him until after June 1976. In October 1976, the parents again asked the hospital for space for the preschool program because they "found" a young qualified teacher who wanted to volunteer Monday-Friday, 9:00 a.m.-3:00 p.m. Mrs. P. sent the Executive Director a memorandum which requested the return of the classroom the children had been given in April 1976; in that same memorandum she wrote:

> . . . Mrs. A. from the TV station news calls me every day to find out if we got the preschool program back at the hospital.

Administrator F was given the assignment by the Executive Director to locate suitable space in the hospital for the handicapped children. He shouted at the staff advisor for not having the parents under control; that the staff advisor and parents had made too many demands on an overworked staff; and that he was not going to permit Mrs. P. to intimidate the administration by her references to her contacts with a television station. (The staff advisor had urged Mrs. P. to mention a television station in the memorandum because he knew that the Administration would respond to the implicit threat of media exposure; yet on the surface it was a truthful statement.)

7. Administrator G--The parents had no contact with Administrator G even after June 1976. This administrator was mainly concerned that the staff advisor "touch base with the right people" since he was accountable for the staff advisor's professional performance. Throughout the time period of the project and up until the present, the staff advisor was never chastised or reprimanded by Administrator G for any specific activity.

Except for Administrator G, the six other aforementioned individuals had a direct involvement with the

activities of the Parents Association. The significant change in attitude for these persons came after the parents were filmed on television in September 1976--the staff advisor learned through the hospital grapevine that everyone was impressed with the parents' ability to capture the interest of a major television station--and they were filmed for a second time two months later during the Thanksgiving season.

Internal Processes

Fiscal

The parents recognized that if they were successful in establishing a preschool program they would need money to purchase either special education equipment (e.g., mats, balance beams, etc.) or transportation services (e.g., hiring a minibus to get children to and from the program). Mrs. P., the chairperson, belonged to a church which was sponsoring a "flea market"--people selling all types of items, used and new, at reduced prices. For ten dollars (i.e., contribution to the church) any organization could purchase a "table" and keep the money from the sale of their merchandise. From January-June 1976, the parents

participated in three flea markets (two under the auspices of a church and one under the auspices of a neighborhood council). By the end of June, they accumulated $325.00. There was some discussion about sponsoring a raffle--but it never got off the ground (because the Association lacked at that time certain resources--prizes, manpower to distribute tickets to the public, etc.).

The parents were proud of their "quick" financial success. They did most of the organizing for the flea markets outside of the scheduled meetings. They called each other at home to set up schedules for rotation--since a flea market typically lasted 8-10 hours. The staff advisor's involvement was limited except for either donating merchandise to be sold at the flea market or giving the chairperson a "pep talk" whenever she called (twice) in a state of panic because she was afraid that the flea market would not be a success.

Formal and Informal Activities

1. Formal--Biweekly meetings at which time parents discussed their plans (e.g., to visit other preschool programs in Brooklyn; to rehearse what they will say at a meeting with community/agency persons); implemented special

projects such as flea markets; planned strategies to get needed resources (e.g., called Administrator E to tell him that the preschool program should be located on the same floor as the Developmental Center; and wrote him a letter which expressed the parents' gratitude so that the Director could feel that he "got" something for his support of the preschool program); interviewed the prospective teacher from the Board of Education; obtained estimates from bus companies to determine how much money would be needed to get the children to and from the hospital: all of these activities transpired during a six month time period --at the formative stage of organizational development.

In May 1976, Mrs. H. introduced the parents to another "new" organization which she had joined. Members from each organization attended meetings of the other organization. Intense discussions took place as to whether the two organizations should or could merge or form an alliance; thereby multiplying limited resources. Personality differences as well as the parents' fear that the new organization will "take over" the Parents Association prevented either a merger or an alliance. The parents felt that since they made a substantial investment in terms of

time and effort to establish their own identity as an organization, they did not want to give it up so easily.

All the activities were clearly geared to one specific goal: to obtain a preschool program. The staff advisor on two or three occasions tried to convince them to have a party so that their spouses could meet and they could relax and enjoy themselves. They politely told the staff advisor that his suggestion was a good idea but no effort was made to plan such a party. It is also interesting to note that at no meeting which the staff advisor had attended did the parents spend time discussing "personal" problems or "ventilating" their frustrations.

2. Informal Activities--Many of the parents called each other frequently on the phone--to discuss issues directly related to the Parents Association as well as to engage in friendly discussions about family, children, recreation, etc. The staff advisor became aware of "visiting" when Mrs. T. told him that she and Mrs. P. visited Mrs. H. "because Mrs. H. sounded extremely depressed for more than a week." Two other parents also decided to visit a special school together so they could compare notes after the visit.

During the time period of the project, the staff advisor never heard parents make any comments about the "personalities" of one another. In November 1976, Mrs. P. and Mrs. T. informed the staff advisor that Mrs. A. "is a nice woman but often speaks in an abrasive tone of voice" and that they were going to try, diplomatically, to change her behavior "so that she doesn't turn people away from the group."

Since all the parents had the experience of not finding suitable services for their handicapped child, they would often exchange information about new services that they read about in the paper or saw publicized on television or about services that they were dissatisfied with. At one meeting the parents complained that "it is a shame that there are so few services and that the professionals fail to publicize the availability of a new service."

Structure

Chairperson-Staff Advisor--Although the parents ocasionally wanted specific items to be discussed at a meeting, most of the agenda items brought to the meeting were the result of discussions between Mrs. P. and the

staff advisor. Because Mrs. P. worked full-time, lengthy discussions took place over the telphone. On two or three occasions both met in a nearby restaurant during Mrs. P.'s lunch hour. By February, Mrs. P. came to the meetings with a written agenda, a list of unfinished business, and a well organized log (which the staff advisor suggested) of all the phone calls and letters which pertained to the activities of the Parents Association.

One of the persistent problems was that the chairperson found herself doing 'all the work' while the other parents often failed to follow-up on things which they said they were going to do. In May 1976, Mrs. C. confided to the staff advisor that she and one or two other parents felt that Mrs. P. was not listening to the suggestions made by the group--and this was one of the reasons why parents often failed to follow-through with their responsibilities. The staff advisor encouraged the chairperson to spend one meeting discussing the structure of the group and morale problems. In late May 1976, the parents met without the staff advisor (who was out sick) and engaged in what the parents described as a "truth" session. They decided that each parent must be willing and prepared

to "speak out" at the time when she is not happy with the way things are going.

What is interesting to note is that the chairperson rarely questioned the staff advisor's suggestions during the six months time period. However, by November 1976, the chairperson not only made suggestions but offered constructive criticisms to the staff advisor.

Because the staff advisor was concerned that the hospital administration might squelch the Parents Association, the staff advisor encouraged only the chairperson to interact with the hospital administrator: because he did not want the administration to feel harrassed by a group of parents. In other words, the administrator might find it easier to deal with one parent rather than with many. On the other hand, the staff advisor encouraged all of the parents to make community contacts within the local community.

Eligibility for Membership and Recruitment

During this formative stage, there were no membership fees or any formal eligibility requirements. Membership was voluntary. There were no penalties for parents who

were contacted but never joined or who joined but only attended one or two meetings.* Both the staff advisor and the secretary were responsible for recruitment of new members, though the staff advisor encouraged each participant to publicize the need for new members. Mrs. T. was given the responsibility to write-up a press release for local newspapers but she failed to follow-up. The staff advisor gave her a mimeographed list of the names and addresses of at least ten local newspapers; made suggestions as to how she can write a simple but interesting story; and offered to revise what she had written since she was concerned about her "grammar." She asked the staff advisor to write the story but he consistently refused.

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*In April 1976 when the Board of Education provided the special education teacher, the chairperson wanted to make a rule that parents of children who are involved in the hospital's program must become involved with the Parents Association. The staff advisor suggested to the parents that they think about the consequences of making participation a prerequisite for a child's entrance into the program. As of the date of this writing, no formal decision has been made. Membership is primarily a voluntary proposition without any penalty imposed on a parent for not joining.

The staff advisor spoke about the Parents Association to parents who had preschool children and who appeared to have some interest in community affairs. At one point he had thought about recruitment of all parents known to the Developmental Center irrespective of the age of their child but decided that including parents whose children are "older" would probably modify or completely alter the primary goal of the Parents Association.

Mrs. T. often used the Developmental Center's telephone to call parents who had never heard of the Parents Association or called to remind parents of scheduled meetings. She also used the office typewriter to type the minutes of the meeting. Mrs. T. said that she felt good whenever she sat in the Center's office--and the Center's clerical staff not only did not complain about Mrs. T's occasional presence in their office but they enjoyed her company and were able to offer her helpful hints on how 'to recruit' people. (One secretary has now become an unofficial recruiter for the Parents Association.

Subjective Sense of Satisfaction with Participation

The staff advisor attempted to elicit from each

parent an individual evaluation of the effectiveness of the Parents Association. Each parent felt that the Parents Association "was doing all that it could do under the circumstances." When the same question was asked after the Board of Education made a commitment to supply a teacher and the hospital promised to furnish a classroom, the parents attributed their success partially to "luck," to "timing," and to their "getting organized." On one or two occasions, the chairperson had publicly thanked the staff advisor for his "showing us who to go to for the right information."

Whereas all the parents found it somewhat difficult to evaluate the effectiveness of their organizational efforts, most parents acknowledged that their attitude towards dealing with professionals as well as their perception regarding the availability of social services for children had changed considerably since their joining the Association. Mrs. P. for example, said that she couldn't believe that "tax money is spent on all types of programs --some very useless and unnecessary--and that programs for handicapped infants and toddlers are almost nonexistent." Mrs. P. became more critical of the federal government for

not overseeing agencies who get federal funds but failed to conform to federal guidelines regarding services to the handicapped (e.g., Headstart only recently has begun to service the handicapped child in spite of the fact that Head Start Centers were under a federal directive to service (10%) handicapped children for the past two or three years).

At the same time Mrs. P. was becoming more aware of how chaotic and fragmented the health system was for children, she felt that her confidence in herself had increased:

> Mrs. P.: When I first began with the parents I was in a shell--psychologically speaking. Not that I am now a "pro" but I remember the first two or three meetings with the Board of Education. I almost died when I had to speak up--sometimes I thought my voice would actually crack. You don't know how appreciative I was, when you [the staff advisor] spoke up for us.

The following are representative statements from some of the other parents regarding how they felt about themselves as a result of their participation:

> Mrs. C.: I am now less afraid to speak up to doctors because I know when I speak up I'm speaking up for all the children.
>
> You should have seen the treatment the doctors give to Barbara when she was an

in-patient when they saw the Chief of Service greet me--because he knew me from the Parents Association. It's who you know that seems to always count.

Mrs. T.: I am less afraid to speak up. I'm not as afraid of professionals as I used to be.

Mrs. A.: I've never been a member in any organization. I'm learning to have more confidence in myself. I want to learn--but slowly. Do you know what? My husband and I now have good long discussions about what the parents should be doing in the Parents Association.

Mother: (Hasidic Mother) My husband does not like me to tell strangers that we have handicapped children --he says it's none of their business. But I think the parents at the hospital are fighting for something the children need. In Europe, there were more programs for handicapped children.

I want to give you staff advisor names of people to contact who I think can help us to get a teacher. I don't care if these people learn about my children.

For many of the parents, participation gave them additional confidence and conviction strength to assert themselves with professionals. In addition, if any parents had any doubts about how things get done, participation in the Parents Association convinced them that "who you know" was

what counts most. There was probably a marginal increase in their cynicism regarding the process of how resources get allocated for individuals in need.

Commentary

This chapter described in detail the Parents Association's participants, its internal processes (which were intrinsic to the Association) and its external processes (which resulted from the Association's interaction with the larger environment). This description was necessary because "the goal of social innovative experiments is to compare the effectiveness of new social subsystems in solving a selected social problem."[5] In other words, another applied-researcher may want to test the outcome by varying an external component (e.g., implant an Association within a total institution rather than a community setting) or by varying an internal component (e.g., involuntary rather than voluntary membership). Since this was a service project, valid generalizations must come from repeated (not necessarily identical) replications--if each replication produces positive results, we can have greater confidence in the reliability of our intervention

(intervention set). Edwin J. Thomas has concluded: "Single-case experimental work has relied heavily and will continue to rely heavily on visual inspection of results and reliable replication as the bases of inferring whether procedures are adequate."[6]

Whereas the previous material gave a full description of the participants as well as the internal and external situation of the Parents Association, this section will offer some explanations as to "why" certain things happened the way they did.

1. It should be no surprise that it was the mothers, not the fathers, who were the participants since it was the mothers who carried the daily burden of caretaking--e.g., keeping in some instances a multitude of clinic appointments. Two husbands, however, informed the staff advisor that they were interested in attending the meetings, ". . . but we feel uncomfortable sitting down with so many women."

One persistent problem was that the mothers who had more than one child or an infant could not obtain nor afford babysitters on a routine basis. It was three mothers--the chairperson, the co-chairperson, and the secretary--who had the best record of attendance, had

unemployed husbands: who babysat for their children while their wives attended meetings. Our country's failing economy provided a favorable situation for consumer participation.

2. Given the fact that the costs of participation were extremely high for the parents, we might infer that it was the participants' overriding commitment to obtain services for their children that prompted them to participate extensively and intensively* despite limited economic resources and serious family difficulties.

3. The flea market as an activity produced a number of benefits because: (i) it required only inexpensive and easy-to-obtain resources--e.g., used merchandise;

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*Participation is a difficult variable to operationalize. One authority made the following distinction:

extensively--the number of roles occupied by an individual in a voluntary association

intensively--specific activities attended by the individual and/or the specific roles he occupies may tell us about the quality of the individual's participation.

In other words, extensive represents quantity whereas intensive indicates quality. See David Horton Smith and Richard D. Reddy in Voluntary Action Research (1972), p. 324.

(ii) relatives* become involved by either donating material or by "rotating" at the flea market; (iii) it gave the parents a feeling of accomplishment because they realized that money is always a necessary resource.

There was, however, another significant benefit which resulted from the parents' fund-raising efforts. The money they raised had to be safeguarded and careful records had to be kept. The Parents Association pyramided its benefits by allowing the hospital's Auxiliary Inc. to become its exchequer: (a) it assured that the Parents Association that its monies were secure; (b) the Auxiliary's President--who was also an active Community Board member became a staunch supporter of the Parents Association and she soon became a reliable informant (for hospital gossip) to the parents and to the staff advisor; and (c) the Auxiliary itself donated new material to the flea markets, and in June 1976 purchased a phonograph for the classroom.

4. The most frequently expressed annoyance with the parents came from individuals from middle-management

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*Mrs. C. had a younger brother in the Navy who donated $25.00 which he collected from his Navy friends.

positions. Their annoyance was manifested usually when they had to respond to a specific request by the parents (e.g., for space, for support on a specific issue, for participation at a specific meeting, etc.). Only Administrator C was consistently negative even when the parents were not making requests (e.g., the staff advisor never posted the Parents Association's publicity flier throughout the hospital because he feared that Administrator C might act irrationally in opposition to the efforts of the parents if he were to daily confront their publicity.

5. Perhaps one of the reasons this association never turned into a social club was that the parents paid heed to the advice of John Gardner:

> And activity in members is directly related to form of organization. It is odd but true that many groups that profess an interest in action are not in fact organized for action. Some, though asserting an interest in action, are organized essentially for study and discussion.[7]

In other words, the parents were small in numbers; their time limited; their objectives clear and concrete; all of their activities were focused on reaching practical objectives.

Notes

1. George W. Fairweather, Methods for Experimental Social Innovation (New York: John Wiley and Sons, Inc., 1967), p. 24.

2. Ray Lees, Research Strategies for Social Welfare (London: Routledge and Kegan Paul, 1975), p. 18.

3. Ibid., p. 19.

4. Delbert C. Miller, Handbook of Research Design and Social Measurement (New York: David McKay Company, Inc., 1970), p. 289.

5. Edwin J. Thomas, "Uses of Research Methods in Interpersonal Practice," Social Work Research: Methods for the Helping Professions, rev. ed., edited by Norman A. Polansky (Chicago: The University of Chicago Press, 1975), p. 279.

6. Ibid., p. 279.

7. John W. Gardener, In Common Cause (New York: W. W. Norton and Company, Inc., 1972), p. 91.

CHAPTER VI

ANALYSIS

This chapter will be a retrospective analysis of the theoretical underpinning of the project. Was it possible to implant a viable auxiliary association within a municipal hospital? How did the contractual agreements, entered into by a number of different parties, change over a period of time? Could the practice principles be implemented? Which theoretical consideration was the most critical for the success (or failure) of the project? What were the unanticipated consequences?

Specific examples or anecdotal material will be presented to support a particular point of view; and whenever possible rival explanations will be considered so that the researcher's personal bias can be at least reduced if not totally eliminated. Neil Gilbert in his book Clients or Constituents, a study of consumer participation in the social service field, discussed three ways he attempted as a participant observer to reduce personal bias

from his analysis: (1) reflecting upon alternative explanations of the events and actions that took place; (2) trying to perceive these events and actions from the perspectives of the various individuals involved; and (3) seeking to observe situations that might offer some degree of comparability.[1]

A Review of the Project's Hypotheses

1. A basic assumption from the outset was that a Parents Association can be created and implanted in the hospital. As of this writing, the Parents Association has successfully "influenced" (through phone calls, memoranda, and personal contacts) the Executive Director to put his signature to a federal grant application for a preschool program for developmentally handicapped children. They have also successfully presented their case to the hospital's Community Board, which has assigned a subcommittee of four members to act as consultants for the Parents Association. By May 1976, various Administrators were "surprised" that the parents had negotiated a special education teacher from the New York City Board of Education; by October 1976, administrators were expressing 'respect'

because the Parents Association had found a qualified teacher (age 26) to volunteer daily from 9:00 a.m.-3:00 p.m. to replace the teacher who had to be reassigned by the Board of Education. The Executive Director called Mrs. P., the chairperson, to apologize for the administration's inadvertent insensitivity by occupying the teacher's office with auditors on the teacher's last day at the hospital.

In January 1976, the Parents Association had received sanction to use the hospital name in its efforts to obtain a preschool program; but by June 1976, the Parents Association had been deeply enmeshed in hospital politics.

Given the fact that by June 1976, the Parents Association had routine "commerce" with the Department of Community Relations, the Auxiliary Association, the Developmental Center, and the Chief of Pediatrics--we may conclude that in fact a Parents Association can be created and implanted in the hospital.

2. What about the principles of normalization--those professional norms which govern the provision of services to the retarded? In April 1976, the hospital had to decide where to locate the preschool program. On the third floor

which catered to a geriatric (and in two or three cases senile) population? Or, on the ninth floor where there was a pediatric acutely ill population? Wolfensberger stipulates the following principle of social integration:

> . . . In order to accomplish the greatest amount of normalization, both by encouraging deviant persons to imitate nondeviant ones, as well as by shaping the stereotypes held by the public of various deviant groups, deviant individuals should have maximal exposure to the nondeviant, and minimal exposure (or juxtaposition) to workers, volunteers, or other individuals who are perceived as deviant themselves by significant proportion of the public.[2]

The parents were not concerned that the third floor was a ward for a geriatric population (female). What mattered the most for the parents--and they were unanimous in their opinion--was that the preschool program should be located near the Developmental Center and other Rehabilitation services such as physical and occupational therapy. By locating the preschool program near these other services (P.T. and O.T.), the children would be "visible" on a daily basis to many different professional staff members--who would be in a position to observe the children on an <u>informal</u> basis. The parents felt that in many instances a practical recommendation by a professional results from informal observation.

The Executive Director, however, wanted to locate the program on the ninth floor. His official explanation was based on the aforementioned normalization principle, though he acknowledged that he did not want to take away space from a ward which was officially allocated for rehabilitation patients. When the staff advisor informed him regarding the parents' preference for the third floor, he could not understand how the parents would be willing "to mix" their children with a geriatric population. The parents felt that "the older people would probably enjoy seeing small children; and the children would not realize that some of these older persons are senile."

In May 1976, the Executive Director authorized the use of an empty ward on the third floor for the preschool program on a temporary basis. As of this writing, the program exists on the ninth floor of the hospital. Although the normalization principle provided a useful framework, viz., that clients who are perceived as 'deviant' should not be supervised by, or located near, another 'deviant' population, the Parents Association was more interested in the short-range immediate advantages which could be obtained for their children than a concern for 'how others

might perceive their children.'

The parents were also willing to accept the preschool program within the hospital rather than a public school because the hospital had more to offer their children: no architectural barriers and clinical support services. In other words, when there was a decision that counterposed a normalization principle (i.e., the social integration of the retarded child with normal children) with immediate benefits to the children, the parents chose the latter.

3. Can a small organization be effective? We can answer this question affirmatively, given the fact that within a six-month period a group of eight to ten parents obtained a preschool program (staff, space, equipment, consultation). As stated in a previous section, the "costs" of participation were high--i.e., family feuding, putting one's job on the line, etc. Substantial "rewards" for participation come only after June 1976, when the parents and the children were televised twice (within a two-month period) and were given a full page feature story in the New York News.[3]

The staff advisor attempted to reward the parents' participation with 'emotional' as well as 'negotiable' rewards.[4] In almost all his conversations the staff advisor praised (e.g., "It's just great that you were able to come") the parents; and whenever possible, parents who participated were given "preferences" for clinic appointments; or if a parent called, the staff advisor returned the call before 5:00 p.m. It was as if the staff advisor used principles of behavior modification (operant conditioning) to reward as well as to encourage sustained participation.

The staff advisor also found himself sharing with the parents intimate details about different people in the hospital (e.g., "Mr. S. gets uptight with consumer groups and more nervous with women") as well as revealing more about himself and his family. The staff advisor and his wife attended one of the Association's flea markets on a Sunday afternoon to show the parents that his interest in their efforts was not limited to Monday to Friday, 9:00 a.m. --5:00 p.m. There is (organizational) merit to Rothman's dictim, "When a practitioner needs trusting relationship to be effective in his work, he may initiate such relations

by risking exposure that can be accepted or rejected."[5]

Some of the reasons for the Association's smallness were: (a) parents who participated did not have sufficient time to attend scheduled as well as community meetings and also spend time recruiting new members; (b) the total population from which to draw new members was relatively small since the Parents Association wanted to attract only those parents with preschool age children; (c) the staff advisor did not want to increase his efforts to recruit new members because he felt that the parents, irrespective of the "costs" of participation, ultimately had to take responsibility for the continuation of their own organization.

Only after the parents were able to "start" the preschool program again--this time with a volunteer--were they able to discuss with more intensity the subject of recruiting and motivating new members. The Parents Association has now decided to charge annual family membership dues and to issue membership cards and to open membership to all interested persons. Losing the Board of Education teacher made the parents realize on an experiential level that a program cannot survive for too long if it doesn't have the potential support of large numbers of people--

hopefully people with political and economic clout.

This project has demonstrated that a self-help group--during its formative stage of development--can be effective in achieving its task objectives with a small cadré of members who participate extensively as well as intensively. As John W. Gardner stated in his recent book In Common Cause, "The citizens' group should treat its membership as a cadre, not a 'bloc' in the electoral sense. The goal is not vast numbers but an active membership that multiplies its effectiveness by reaching out into the community."[6]

4a. Norm of Reciprocity and Exchange Theory. If there were one theme which reared its head again and again throughout the duration of the project it was 'who owes whom?' Both the parents as well as the hospital kept a 'mental scorecard' of assets and debits. From the outset, the hospital made it clear that the parents were not to request any resources except for meeting space and a staff advisor. Not only were the parents to refrain from seeking resources from within the hospital, they were requested, in return for using the hospital as a base of support, to provide the hospital with a tangible program, which could then

be publicized and hailed by the hospital's Community Board. The parents accepted the terms of this contract--which were made explicit at the first few meetings held in the Community Relations office. They accepted it because they needed an organizational base from which to operate. Only after the Executive Director signed the letter of agreement with the Board of Education did the parents begin to make demands on the hospital--e.g., that the preschool program should be located on the third rather than the ninth floor; that the Developmental Center and the Rehabilitation medicine Department should consult with each other more frequently; and that the hospital's Physical Therapy Department should not rotate its staff with developmentally handicapped preschool children.

What prompted the parents to act so boldly, i.e., in making these demands, was their belief that they have generated positive publicity for the hospital and, most importantly, generated additional income for the hospital by giving the hospital a new program. Behind this calculus of 'how much we owe each other' loomed the power factor. The parents recognized that the Executive Director, now that he signed his name to a quasi-official letter of

agreement, was constrained to support the program; whereas the parents felt initially that the administration could justify the Association's disappearance from the hospital for even the slightest 'annoyance' caused by the Association, the parents now felt that they could begin to make "waves" and still survive as a hospital-based group.

The waves got larger as the parents felt they accumulated more assets as well as more power. For example, when they found a volunteer to replace the Board of Education teacher, they requested the return of the classroom and the teacher's office. Recognizing that the hospital might be only willing to allocate a scarce resource (viz., space) for a program which involves another major institution (viz., Board of Education), the parents made certain that the Executive Director and his associates were aware of their close alliance with a television station. The parents got the room and office for the volunteer, but the staff advisor was admonished by an administrator not to forget that the hospital has given the parents everything and the parents have given the hospital nothing but "headaches" and "requests." Although the parents were able to escalate their requests as they felt they possessed the

resources or the power of both, they studiously avoided the use of confrontation tactics and always presented their requests in a direct but always urbane manner.

This predilection to avoid confrontation and to be polite and urbane was a function of the personalities of the participants involved (at meetings rarely did the parents use terms as "fight," "protest," or "let's get them")* but also a function of their recognition that they perhaps needed the hospital more than the hospital needed them. The parents never wanted to win pyrrhic victories!

4b. Pyramiding Resources. As soon as the Board of Education indicated in writing their interest in staffing a preschool program at the hospital, the parents and the staff advisor were able to begin to "pyramid" resources. As Weissman has stated in his analysis of neighborhood councils:

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*On one or two occasions Mrs. C. would jokingly suggest that the parents use a more militant and dramatic strategy to reach their objectives. Whenever this occurred, the staff advisor warned in a tone of solemnity that the goal of the Parents Association was not 'action for the sake of action' so the prospect of more militant action was immediately discouraged by the staff advisor.

> . . . Resources do not have to be directly recruited for the project at hand; nor do they have to be immediately available to complete the project successfully. It [neighborhood council] attempts to recruit for another project resources that could be pyramided for use in the first.[7]

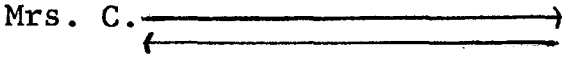
Example 1. Mrs. C. became interested in the hospital's Community Board and wanted to become a member of the Board. The staff advisor began to coach Mrs. C. for a Board screening interview, and helped her complete a membership application form. On the application form Mrs. C. wrote: "My participation in the hospital's Parents Association For Developmentally Handicapped has helped me to learn about community resources and how all children suffer when our community does not get adequate delivery of health care services." Mrs. C. applied for membership as soon as the staff advisor had heard from the Community Relations office that the Board needed new members from certain geographical areas. Mrs. C. was accepted (received an endorsement from the President of the hospital's Auxiliary who had been a strong supporter of the Parents Association). The Parents Association then used Mrs. C. as a channel for "inside information"; and they also expected Mrs. C. to plead their case to the Community Board. This dual role,

as a member of the Parents Association and a member of the Community Board, has created role strain for Mrs. C.: since she now feels that she is a "spy" for the Parents Association on the Community Board.

Example 2. The staff advisor used the fact that the parents were trying to raise money for a preschool program to obtain authorization from the Bureau of Mental Retardation and the hospital's affiliation Administration to attend a one week grantsmanship training program. After he attended the program, the staff advisor was requested to "brief" a number of administrative staff and Chiefs of Service (Pediatrics and Psychiatry) at a special meeting regarding the content of the training program. The staff advisor used this special meeting to publicize the efforts of the Parents Association and to get helpful hints about how to apply for federal state grants.

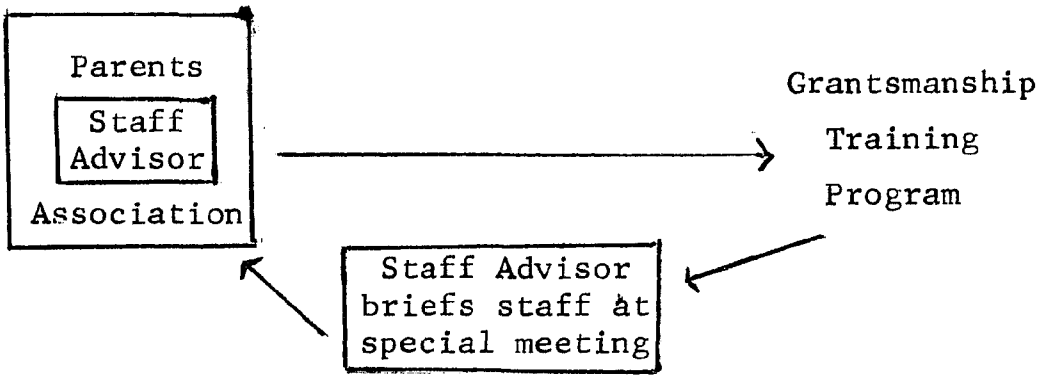
We can summarize the above two examples diagrammatically:

Example 1



Mrs. C. used her experience with the Parents Association to become a member of the Community Board and in turn has used the Community Board to support the efforts of the Parents Association:

Example 2



The staff advisor used the Parents Association as a justification to attend a grantsmanship training program. He was then invited to brief his colleagues at a special ad hoc meeting--which the staff advisor in turn used to publicize the activities of the Parents Association and to gather information which might be helpful to the parents.

5. Was a community development approach operative for this project? Was the staff advisor able to follow the practice principles outlined by Kurzman (see Chapter 3): advocacy------→ community development-----→ consultation? Was the staff advisor able to become less involved with

the parents as he anticipated (see Fig. 4.2 for a hypothetical example of a practitioner's involvement over a period of time)?

Rothman's Community Organization Variables

In his article, "Three Models of Community Organization Practice," Rothman lists twelve "selected" variables: (1) goal categories of community action; (2) assumptions concerning community structure and problem conditions; (3) basic change strategy; (4) characteristic change tactics and techniques; (5) salient practitioner roles; (6) medium of change; (7) orientation toward power structure; (8) boundary definition of the community client system or constituency; (9) assumptions regarding interests of community subparts; (10) conception of the public interest; (11) conception of the client population or constituency; (12) conception of client role.[8] All of these twelve variables are either directly or indirectly affected by the organization which employs the professional. What follows seriatim is an analysis of these twelve variables vis a vis the Parents Association.

1. Goal categories. Throughout the formative stage of the project (January 1976-June 1976), the primary goal for the parents and for the staff advisor was concrete and clear: obtain a preschool program for developmentally handicapped preschool children. At one or two meetings the staff advisor attempted to get the participants to think about goals over and beyond the preschool program. But the parents were only interested in task objectives such as finding adequate resources that could be utilized for a preschool program.

There were two instances, however, where the Chairperson 'moved' the Association to a "watchdog" role. Mrs. P. was angry over the fact that certain agencies mandated to serve handicapped children were either hiding behind long waiting lists or using outdated restrictive intake policies. In March and April 1976, the parents sent letters (drafted by the staff advisor) and telephone calls were made to demand explanations from these agencies as to why so many handicapped preschool children were excluded from their programs. After having received many telephone calls from Mrs. P. as well as letters (with copies to strategic people), the local Head Start Center began to

respond positively by accepting (in September 1976) retarded preschool children referred to them by the hospital's Developmental Center.

It should come as no surprise that the Parents Association was focused on 'task' goals, i.e., "solution of a delimited problem,"[9] because that was the parents basis for joining; and the costs of participation were too high for there to be any goal displacement. In addition, by focusing on this one specific narrow goal, which was perceived by both hospital and nonhospital staff as normatively acceptable as "apple pie" and "motherhood," the Parents Association was able to make a legitimate claim for resources from a variety of institutions.

2. Assumptions concerning community structure and problem conditions. The staff advisor's basic assumption was that the Parents Association possessed the potential capacity to influence local institutions: because 'power' over the distribution of certain resources was not centralized: that there was not one "power elite" but a number of power centers throughout the community: a pluralistic power structure "within which democratic processes and democratically elected officials constitute at least

one of several powerful elements."[10] From January-June 1976, the parents were able to contact these various power structures (i.e., the educational establishment, the mental health establishment, etc.) to either obtain resources or to obtain sanction for their activities.

As of this writing, the Parents Association has recognized, particularly Mrs. P., that the power structures within the local community are controlled or, at least, affected by power centers more distantly removed from the local community. The parents came to this recognition when they discovered that all the local institutions which deal with children have, in fact, no formal programmatic responsibility for developmentally handicapped preschool children, particularly severely/profoundly retarded children.

3. Basic change strategy. From January-March 1976, the parents used small-group meetings ("rational discussion") as a modus operandi to accomplish their objectives. It was not only the content of the meetings which was important but of equal importance was the "timing" of the meetings, the "sequence" of the meetings and the "composition" (who attended). The staff advisor's basic strategy, from January to March 1976, was, to create a 'momentum'

which would heighten the consciousness of certain key persons inside and outside of the hospital, which in turn would create an "encouraging environment" for the objectives of the Parent Association. At no point did the parents seriously entertain any other strategy except "rational" or "reasonable" discussion.

This emphasis on 'rational' and 'reasonable' action could be related to certain organizational variables. In their Sociology: A Biographical Approach, Peter L. Berger and Brigette Berger have stated, "In order to cope effectively with a bureaucratized world, the individual must continuously keep in control various emotions, such as affection, hatred, impatience, enthusiasm or anxiety. In other words, a bureaucratized world, expects him to be 'reasonable' at all times."[11] Given the fact that the hospital in which the Parents Association was implanted had a history of "fighting" local community groups; and given the fact that the hospital's primary mission was the provision of direct health services and not the sponsorship of community action groups; any other strategy--such as a social action approach--could not have been adopted by a hospital-based Parents Association, particularly during

its formative stage.

The community development model was congruent with the hospital's conservative approach towards its social environment--it was as if the hospital had adopted a 'foreign policy' of peaceful coexistence. During the Parents' Association formative stage, a community development model was an effective strategy. After September 1976, however, the parents found themselves in a quandry: how could they publicly protest the fact that the Board of Education violated its commitment to the parents by removing the special education teacher, without any embarrassment to the hospital and, more importantly, without any jeopardy to the hospital's ongoing contractual arrangements with the Board of Education? When the hospital's Executive Director, for example, was informed by the staff advisor that a television station wanted to do a story on the parents' efforts to establish a preschool program, the Executive Director, though sympathetic to the parents' situation, reminded the staff advisor "to be careful not to put the Board of Education in a poor light since the hospital has other joint programs with the Board of

Education."* The parents have been walking a tightrope between 'fighting' for their objectives yet not alienating the hospital's administration: because the hospital has been the only major community institution which has made an oral as well as written commitment to the medical/social needs of developmentally handicapped children.** Rothman has noted that a practitioner must realize that not only do some situations necessitate the implementation of (say) a community development model and a planning model simultaneously; but that one model may be appropriate for a given period of time until circumstances dictate the use of a different model:

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*Like most hospitals, there was a Board of Education teacher assigned to the Pediatric ward for those children whose hospital stay was prolonged. Only two or three months later did the staff advisor learn that another hospital department was negotiating with the Board of Education for a program (which was to be located at the hospital) at the same time that the Parents Association lost their Board of Education teacher.

**In February 1977, the Executive Director, in a covering letter attached to a federal grant application, wrote that the hospital has made a commitment to developmentally handicapped children by both word and deed.

> In addition to mixing, there is a phasing relationship among the models. A given change project may begin in one mode and then at a later stage move into another. For example, as a social action organization achieves success and attains resources, it may find that it can function most efficiently out of a social planning model.[12]

The parents have attempted in recent months to mix a community development approach with a social action approach (two dramatically opposed models) by letting certain social action groups assume the responsibility for social action. Another study would be necessary, however, to examine how effective such a "mixed" approach proved to be.

4. Characteristics change tactics and techniques. Whereas the overall strategy was small-group discussion (from January to June 1976 there were 15 scheduled meetings as well as 4 ad hoc meetings outside the hospital and 9 meetings inside the hospital), the major tactic utilized was the collaboration between the staff advisor and the chairperson--where either the staff advisor or Mrs. P. would contact a staff person within or outside the hospital; or a memorandum would be written signed by either the chairperson or the chairperson and the staff advisor.

The staff advisor's approach was to issue as many memoranda signed by the chairperson so that with each

written memo the hospital would be less inclined to consider the elimination of the Parents Association. Only once did an administrator admonish the staff advisor for sending a copy of a memo to the Parents Association; he felt that the parents need not concern themselves with internal hospital matters. That same administrator was also annoyed* when Mrs. P., the chairperson attended a meeting convened by a Chief of Service. Thereafter, throughout the formative stage, the chairperson did not get any invitation to participate at "internal" meetings; however, the staff advisor gave the chairperson comprehensive reports on each meeting and always requested her opinions on "significant" matters.

Was the parents' participation meaningful? According to William Ryan, "advisory boards of all sorts--from urban renewal and poverty to community mental health centers--are rarely representative in any sense whatever, and they are

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*The staff advisor was told about the administrator's annoyance by the Chief of Service, who had given Mrs. P. the sanction to attend this particular meeting. But it was the staff advisor who had encouraged Mrs. P. to ask the Chief's permission to attend.

usually asked to react to, rather than participate in decisions."[13] From Ryan's perspective, the parents' participation within the hospital was superficial because they only reacted to rather than formulated decisions. On the other hand, Specht views participation on a continuum of passive -----→ active. On the active scale, he postulates "democracy by veto":

> The process might be termed "democracy by veto," since real influence is only exerted when the citizens reject a public plan. In practice this is often not an all-or-nothing situation. Plans that are rejected may be modified and again brought before the citizens. When this occurs, the function of participation moves into the next category [actual shaping of public decisions].[14]

Both Ryan's and Specht's formulations contain implicit value judgments--this or that type of participation is 'good' or 'bad.' To avoid these implicit judgments, another 'more' neutral framework will be utilized. Within any organization change can affect at least four structural levels: (a) specific actions; (b) decision-making rules; (c) institutional structure it used to make those rules; and (d) the basic organizational mandated goals.[15] The Parents Association made an impact on specific actions of the Development Center as well as on other hospital departments in addition to altering a decision-making rule--viz., that

the staff advisor must consult the Parents Association on matters which pertain to developmentally handicapped preschool children. That the parents succeeded in making such an impact can be attributed to the influence they accumulated in a relatively short period of time. Why didn't they change the decision-making structure? or the basic organizational goals? There were two reasons: First, the Parents Association was only interested in gathering resources for a preschool program, not in remolding the hospital. Secondly, "it is easier to adjust actions than rules, easier to shift rules than change structures than adopt new purposes."[16] In other words, even if the Parents Association felt the necessity to alter the decision-making process, they did not possess sufficient power to change or modify either the hospital's decision-making structure(s) or its primary mission of direct health care delivery.

5. Salient practitioner roles. In Chapter V, the design of the project stipulated three primary functions for the staff advisor: salesmanship--promoting the activities of the Parents Association within and outside of the hospital; navigation--referring the parents to the right person; teacher --through coaching, role-play, or didactic instruction: skills

such as chairing a meeting, taking minutes, speaking to a bureaucrat, etc.

During the formative stage, the 'teacher' function was preeminent from January to March 1976. The staff advisor had numerous, lengthy telephone conversations with Mrs. P. regarding the need for an agenda, for getting agenda items from the participants themselves, for delegating certain responsibilities to the other participants so that the leadership function can be lodged throughout the group rather within one individual, etc. He also had many impromptu meetings* with Mrs. T., the secretary, regarding minute taking (what gets into minutes as well as what one leaves out) and the different approaches toward motivating attendance and active (i.e., intensive) participation--since Mrs. T. often wanted to take a hardline approach, viz., that people should be told that they must participate or that any parent who did not respond to a meeting notice should be

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*Initially, the meetings were impromptu because Mrs. T. would come into the staff advisor's office while her child was being seen by a therapist. After two or three such unscheduled meetings, the staff advisor purposely left his calendar clear to see Mrs. T. on the day her daughter was in therapy.

automatically dropped from the membership register.

In terms of expenditure of time, the staff advisor, was doing more teaching than selling or navigating from January to March 1976. He did introduce, however, the parents to a number of school officials, and to parents from other local organizations; and he spoke with a number of administrative staff from both the public school system and from a private school for special children about the Parents' Association meritorius goals. The fact that from January to March 1976, it was still uncertain which institutions in the community would contribute resources for a preschool program, gave the parents more time to learn by doing--e.g., attending a meeting held outside the hospital in the Deputy Superintendant's office--inviting the President of the hospital's Auxiliary to the Association's scheduled meeting; etc. It also allowed the staff advisor to pay heed to Kurzman's practice principles* for assisting an oppressed group. The staff advisor would purposely--particularly at meetings with the Board of Education--speak in a vigorous and bold fashion so that the parents might be

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*See Chapter 2.

inspired (or infected) by the staff advisor's conviction. After a few of these meetings, the parents would exclaim to the staff advisor that they were so happy that it was the staff advisor to whom the official addressed his question; or a mother would tell the staff advisor how difficult it was to "get a word out." (These same parents are now able to give interviews with reporters without the staff advisor present and are able to appear on panel discussions.)

It was after the hospital agreed to provide space for the preschool program (March 1976) that the staff advisor became preeminently a navigator--constantly giving the parents, particularly, Mrs. P., inside information on how they could negotiate the hospital system--who to call, who to write a memo to, who to meet with on a face-to-face basis, who <u>not</u> to call, etc. The staff advisor's purpose in giving out this type of information was not necessarily to <u>educate</u> the parents on how the hospital works but information which they in turn could use to <u>constrain</u> the hospital to either act or not act in a certain way. From March to June 1976, the operative model for the staff advisor was not a community development model but a "guerilla in the

bureaucracy" model:

> But suppose the community has an insider--like the community planner--who not only understands all this red tape but also has access to information about the city's activities in the community. Through him, the results can lay their hands on the weapon of information and attack unwanted city policies at their weakest points.[17]

Every bureaucracy has its secrets which are privy only to its staff. In the same way a staff can sabotage their employer's request for the implementation of a new policy directive by 'going by the book,' i.e., adhering strictly to antiquated established procedural minutia, the staff advisor was able to put the hospital administration 'on the spot' by giving the parents office secrets.

5b. Role strain. One of the hypotheses of this project was that the staff advisor would experience role strain as a result of the varied and conflicting demands made on him by different parties (parents, hospital administration, and colleagues from the Developmental Center).

One strain that was experienced by the staff advisor throughout the duration of this project was that he was still responsible for certain casemanager functions as well as intake interviews for families who came to the

the Developmental Center for assistance. Since there are only "x" hours in a day, the staff advisor had to find a way to fulfill his role as the Center's Social Worker and to find the time to fulfill his "new" role as "staff advisor" to the Parents Association. This issue of time allocation had, to some degree, a "life and death" quality to it because all programs in the hospital were concerned that without "good statistics" (i.e., large number of interview sessions) a program or service would find itself in a vulnerable position at a time when city and state officials were looking for programs to cut. The staff advisor resolved the problem, administratively, by "counting" each parent who attended the bimonthly meeting on his monthly statistical form. On the other hand, we can only surmise what the opportunity cost was--that is, how many other parents of handicapped children who needed either counsel or resources or both did not receive it because the staff advisor had decided to allocate more time (i.e., a limited resource) to the Parents Association. Although the staff advisor always found "some" time to assist parents who requested his intervention, he rarely found

the time to contact parents whom he did not hear from--which he used to do as a routine practice prior to the creation of the Parents Association. Realizing that he was not getting feedback from some parents, the staff advisor would constantly ask his colleagues (e.g., psychologist, speech therapist, pediatrician, psychiatrist) if they had heard from this or that parent. In other words, getting feedback from his colleagues was a functional equivalent (which involved less time) for calling a parent.

So long as the staff advisor and the efforts of the parents were focused outside of the hospital (from January-March 1976), the staff advisor did not experience any role strain which was the resultant of "conflicting" demands. However, as soon as the preschool program was located at the hospital, the staff advisor began to be "pulled" in different directions--for example, the parents wanted the third floor as the location for the program; the Chief of Service wanted the third floor because he did not want it on the ninth floor (pediatric service); and one Affiliation Administrator wanted the program on the ninth floor because he was engaged in a power struggle with the Chief of

Service. In this particular case, the staff advisor informed the parents that he did not want to take a strong stand because he felt either the third floor or the ninth floor would be a "suitable" space for the children--each floor possessing certain advantages as well as disadvantages. But he also confided to the parents that the space issue was being used as a smokescreen for a power struggle and that he (staff advisor) did not want to be "scorched" in the process.

Since the space issue (i.e., third or ninth floor) there were other times when the staff advisor confided to the parents that he was concerned about his position within the hospital. There is much validity to Cloward's comment, "It is not easy to be a bureaucrat, intent on rising within the bureaucracy and side with the clients and victims of that bureaucracy."[18] The staff advisor in one instance informed Mrs. P. that he did not want her to "jump the line" because he feared that the lower-level administrator would harass him. By using the parents' complete confidence and loyalty to the staff advisor, the staff advisor was able to lessen the parents demands on him whenever these

demands conflicted with the hospital administration.

In the same way that it may be axiomatic that agency "Y" will hold agency "X" responsible for the militant action of a grass-roots group, it may be equally axiomatic that agency "X" will hold the staff advisor responsible for any "irresponsible" or "troublesome" behavior of the consumer group. On at least three occasions the staff advisor was either warned directly or cautioned indirectly that he was expected to "influence" the actions of the parents. The staff advisor reacted by never responding apolegetically--he did not want to have himself perceived as an individual who could be intimidated. He also would demand a counter-proposal from the administrator --what s/he would do if he were in the parents' situation. Sometimes this latter approach would force the administrator to take a more 'understanding' position. Nonetheless, the staff advisor was always mindful that, irrespective of the 'rightness' of the parents' actions, the hospital administration would always assume that the staff advisor either encouraged this or that action or did not use his influence to get the parents to do something else.

5c. In Chapter IV, Fig. 1 indicated a hypothetical course of professional involvement over a period of time. By March 1976, the parents were able to conduct a business meeting; the secretary knew how to take minutes; the chairperson knew how to prepare an agenda and how to elicit suggestions from the participants; therefore, the staff advisor did not have to devote as much time teaching these aforementioned skills after March 1976. In April 1976, however, when the Board of Education gave the parents and the hospital a special education teacher and a $400.00 allotment for the purchase of equipment, the staff advisor spent as much time teaching the parents 'how to operate' a program as he once did teaching them administrative skills (on conducting meetings). For example, the staff advisor conducted rehearsals with the parents so that the parents would know what questions to ask when they interviewed the Board of Education teacher--before the parents decided to officially accept her at the hospital. Then there was a question as to whether there would be a "fee"-- which involved issues such as Medicaid payment vs. non-Medicaid; a hospital program vs. Board of Education program. The staff advisor had to help the parents to see that each

solution had consequences not only for each individual family but for the hospital as well as for the Parents Association! From January to June 1976, the staff advisor devoted at least 8-10 hours per week to his work with the Parents Association; what changed was how he used those hours over this period of time.

6. Orientation toward power structure. Rothman states, "One consequence of this [members of the power structure are considered to be collaborators in a common venture] might well be that in Model community development only goals upon which there can be mutual agreement become legitimate or relevant, the goals which involve incompatible interests are ignored or discarded as inappropriate."[19] Although the parents never specifically stated what their orientation was toward the "power structure(s)," they did believe that either pressure from consumer groups, money, or political pressure was often necessary before an agency or institution would surrender a resource, yield on a policy issue, or condemn an established practice. The parents contacted only those agencies or persons which had some direct relationship with services for children or for children with developmental handicaps. They always approached an agency or a key person

on two levels: (i) overtly--that the agency wanted to act in the best interests of handicapped children; and (ii) covertly--that the agency will do what it needs to do for itself. In other words, we may infer from the parents' actions and words that their orientation toward the power structure was: though they did not believe in a monolithic power structure ("them"), they did harbor a strong suspicion of distrust toward agencies/institutions; an agency was guilty until proven innocent, even an agency with a clear mandate to service handicapped children.

7. Boundary definition of the community client system or constituency. In a classical community development project, the neighborhood or the block represents the object as well as the context for change. For this project, geography was an important contextual factor. The Parents Association argued effectively that a handicapped child's chance for services (and improvement) was based on "accident of birth"--the unfairness of the fact that children who lived only in certain areas had access to specialized preschool programs. Geography was a significant parameter for another reason--it was a small enough area for parents to meet informally in the streets while (say) shopping or to

visit one another without travelling long distances; it indirectly increased organizational morale.

8. Assumptions regarding interests of community subparts. The Parents Association did not live under the illusion that all agencies/institutions shared the same goals or that these diverse goals were "basically reconcilable and responsive to the influences of rational persuasion, communication, and mutual good will."[20] The parents insisted that each agency conform to its stated goals and whenever possible used the New York City Department of Mental Health and Mental Retardation as a leverage for manipulation (power) since it was the agency which set standards and monitored contracts with voluntary as well as public facilities. As stated in item 6, the parents never thought for a moment that an institution or agency would be charitable for the sake of being charitable--even when the agency accepted in toto the objectives and goals of the Parents Association. What was most frustrating for the parents to constantly hear was that no one agency or institution was responsible for services for handicapped preschool children, though everyone was in full agreement that such programs were needed on both the 'goodness tests' (viz., that such programs could substantially

improve the functioning of handicapped children) and the 'efficiency test' (viz., that such programs were less expensive than programs in institutions).

9. Conception of the public interest. The parents never felt that they had to justify their involvement in the community as advocates for increased services for handicapped preschool children. They believed in the democratic ethos as exemplified in the Biblical proverb, "Let us sit down and reason together," though they recognized that not everyone at the table was equal in terms of power. To use Rothman's analytical framework,[21] the participants shared two diametrically opposite viewpoints: (a) rationalist--through rational discourse which involved many parties a fair solution can be found; and, (b) realist--public policy was determined by a balance of power. The parents recognized that rational discourse without the accumulation resources was an exercise in futility; that the democratic ethos or the American credo was not in opposition to the accumulation of (or competition for) resources.

10 and 11. Conception of the client population or constituency. The parents viewed themselves as consumers (recipients) and therefore responsible for determining what

services were required for their children and how these services were to be defined. In fact, they used their role as "parents" in general and as "mothers" in particular to justify their basic right to vigorously demand services in behalf of their children. The role of parent, not that of 'citizen' or even 'consumer,' was the overarching role.

Using Rothman's framework as a heuristic model, the Parents Association was congruent with a community development model except for three variables: (a) geography--more of a contextual factor than an object for change; (b) power structure--recognized that institutions were not inherently malevolent; on the one hand, that they do respond to rational discourse; on the other hand, rational discourse had a greater impact when it was accompanied with some degree of power; (c) that they justified their involvement as well as their claim for a preschool program on the basis of their role as parents--not as citizens per se.

Unanticipated Consequences

Unlike the physical sciences, no social science theory has given us the ability to predict with unfailing accuracy that under conditions "X," "Y," and "Z" or any

combination or permutation thereof a certain outcome will result. Over and beyond the limitations of social science theory, a long-range plan with precise details can rarely be implemented in a democracy because as Etzioni has stated, "democracies must accept a relatively high degree of incrementalism because of their greater need to gain support for new decisions from many and conflicting groups, a need that reduces their capacity to formulate and follow a long-run plan."[22] There was, however, only one unanticipated consequence during the formative stage (January to June 1976), but many unanticipated consequences after June 1976; (a) After giving the parents/hospital the teacher in April 1976, the Board of Education removed the teacher on September 13, 1976 with only one week's advance notice; (b) That Mrs. F., an active participant used her relative to get the Association television coverage on a major network--parents and children were filmed twice within a two month period; that Mrs. A., an active participant, had a relative in a high position in the U.F.T. (teacher's union) who began to exert pressure through the media; (c) That through the publicity the parents found a qualified volunteer to work with the children on a daily basis; (d) That by June 1976,

the staff advisor was gaining access to certain hospital channels of communication which were never open to him before the creation of the Parents Association.

The one unanticipated consequence which occurred during the formative stage (January to June 1976) was the fact that since Mrs. P., chairperson, was still looking for a preschool program for her 3 1/2 year old son, her situation acted as a constraint as well as a source for change. It was a constraint because she was reluctant to publicize her role as chairperson as well as her active participation in the Parents Association "because professionals do not like to deal with troublemakers so I'm not going to take any gamble until I get my child into an established preschool program." It was a source of change because she requested, in her capacity as chairperson, that certain practices in the hospital be changed: "I can't see how my son as well as other children are treated by two departments and the staff of both departments rarely talk things over except on an occasion in the corridors." Now that Mrs. P. has her son enrolled in an established preschool program (two years on a waiting list), Mrs. P. has taken a bolder stance on more issues than she had done

previously.

The fact that there was only one unanticipated consequence from January-June 1976 but many thereafter indicates that the project's theoretical underpinning and the practice principles were applicable only throughout the formative stage of development. That we would need to develop another model as the Parents Association moved from an embryonic and fetal stage to the stage of neonate.

Process and Task Goals

This project has demonstrated that we should not view process and task goals as two different coins but rather as two sides of the same coin. As the parents acquired resources to establish a preschool program, they were also acquiring the influence (or power) they needed to make themselves creditable as a viable hospital-based group; the acquisition of the task goal (preschool program) gave the parents the opportunity to achieve a significant process goal (institutionalization within the hospital). When the parents lost the teacher (the task goal) in September 1976, they were in a position to influence the hospital (process goal) to get the Administration to

submit an H.E.W. demonstration grant ($70-120,000) for a preschool program for developmentally handicapped children (task goal). Task or process goals were primary at different points in time. From the parents' perspective what counted most was the task goals but from a larger systemic perspective, what also counted was the firm implantation of the Parents Association within the hospital system.

Contractual Arrangements

Explicit as well as implicit contractual arrangements change--we might state that observation as a postulate: contractual arrangements will change as the participants and the social situation change over a period of time. Whereas the Bureau of Mental Retardation was an active force--by sending a Senior Consultant to some of the meetings which the parents had attended and by giving the staff advisor verbal authorization to attend a five-day grantsmanship training program--it was no longer an active force by April 1976: when the Bureau experienced an almost 100% staff turnover and has not completely recovered as of this date. On the other hand, the hospital's Community

Board only became an active force in September 1976; and it was only by serendipity that the Community Board became involved on an ongoing basis. When Mrs. P. was given an invitation to attend a Community Board meeting, it was expected that she would tell a success story: How the hospital and the Board of Education obtained a needed program for and within the local community. But Mrs. P. had another story to tell--how after much effort and even with a 'letter of agreement,' the teacher was removed. The Community Board responded with an outpouring of suggestions mixed with sympathy; but, more importantly, they created a permanent subcommittee which was to be a source of consultation for the Parents Association.

The affiliation administration which was most helpful from January-June 1976, was no longer involved by November 1976. The Affiliation Administrator left for another job only to be followed by the announcement that the affiliation contract was no longer to be effective after June 1977.

Carol Weiss has stated that any given program's objectives should have meaning to the program's relevant constituencies.[23] Although it was not clear as to 'why'

the Executive Director agreed to sanction the existence of the Parents Association at the outset, it became clearer through the verbal statements of the staff who were close to him that he wanted to show the Community Board that he was in fact receptive to community groups; and that he was looking to the Parents Association as an (eventual) source of resources for the hospital. In October 1976, one administrator shouted at the staff advisor, "We're tolerating your zealousness and the parents' requests because we know that it may bring a 'buck' into the hospital." The parents were not offended by the fact that the hospital expected something in return because they felt that the relationship between the hospital and the Parents Association would be more equitable on a basis of 'reciprocity,' than on 'beneficience.' By June 1976, the Parents Association gave the hospital positive publicity and the prospect of more income--because middle-income people who never came to a municipal hospital began to call the Developmental Center because they had heard about the preschool program which was established at the hospital.

The Development Center staff were not directly involved in the creation of the Parents Association. The

professional staff has had a favorable attitude throughout the duration of the project because they recognized the need for a specialized preschool program. After September 1976, a discernible negative attitude had developed. All the publicity on television as well as in the newspapers either ignored or paid very little attention to the existence of the Developmental Center. As one psychologist put it, "What is the Center getting out of this publicity? We all know that if it were not for the staff advisor and the support of the professional staff, the Parents Association would not likely be in existence." Although the parents did in fact give considerable credit to the Developmental Center in their interviews, the media has given the parents the spotlight and placed the Center in the parents' shadow. Here is one instance where the parents have not been able to "repay" the Center for its support.

Notes

1. Neil Gilbert, Clients or Constituents (San Francisco: Jossey-Bass, Inc., 1970), p. 179.

2. Wolf Wolfensberger, Normalization (Toronto: National Institute on Mental Retardation, 1972), p. 35.

3. Bert Walker, "No City Help, Moms Train The Disabled," Sunday News, 2 January 1977, p. 1K.

4. See Chapter II, Theoretical Frames of Reference.

5. Fred M. Cox et al., eds., Strategies of Community Organization: A Book of Readings, 2d ed. (Illinois: F. E. Peacock Publishers, Inc., 1974), p. 404.

6. John W. Gardener, In Common Cause (New York: W. W. Norton and Company, Inc., 1973), p. 91.

7. Harold H. Weissman, Community Councils and Community Control: The Workings of Democratic Mythology (Pittsburgh: University of Pittsburgh Press, 1970), p. 132.

8. Jack Rothman, "Three Models of Community Organization Practice," Strategies of Community Organization: A Book of Readings, 2d ed., edited by Fred M. Cox et al. (Illinois: F. E. Peacock, Inc., 1974), pp. 26-39.

9. Ibid., p. 27.

10. Peter L. Berger and Brigette Berger, Sociology: A Biographical Approach (New York: Basic Books, Inc., 1972), p. 274.

11. Ibid., p. 208.

12. Rothman, p. 38.

13. William Ryan, Blaming the Victim (New York: Vintage Books, 1971), p. 269.

14. Gilbert, p. 33.

15. Anthony Downs, Inside Bureaucracy (Boston: Little, Brown and Company, 1967), p. 167.

16. Ibid., p. 173.

17. Martin L. Needleman and Carolyn Needleman, Guerillas in the Bureaucracy: The Community Planning Experiment in the United States (New York: John Wiley and Sons, 1974), p. 132.

18. Richard A. Cloward and Frances Fox Piven, "Notes Toward a Radical Social Work," Radical Social Work, eds. Roy Bailey and Mike Brake (New York: Pantheon Books, 1975), p. xiii.

19. Rothman, p. 32.

20. Ibid., p. 33.

21. Ibid., p. 34.

22. Amitai Etzioni, Social Problems (Englewood Cliffs, New Jersey: Prentice Hall, Inc., 1976), p. 94.

23. Carol H. Weiss, "Alternative Models of Program Evaluation," Social Work 19 (November 1974): 679-680.

CHAPTER VII

POLICY AND PROGRAM IMPLICATIONS

The Implementation Process

The practitioner who intends to replicate this project by working with a local self-help group at its formative stage of development has to know and understand those factors and processes which either facilitated or inhibited the progress of the Parents Association. Why was there such quick success (e.g., obtaining a special education teacher) and then such a quick loss (e.g., losing the teacher)? What was the nature and quality of the staff advisor's role? Advocate? Broker? Enabler? Or, something in between? By raising such questions, this writer intends to factor out recommendations which, hopefully, can help a professional to cross similar (not necessarily identical) terrain but with less risk for failure.

In his book, Promoting Innovation, Rothman suggests

frameworks (or action guides) by which to analyze "promoting an innovation"[1] and "increasing the effectiveness of role performance."[2] These frameworks will be applied to the Parents Association since the association can be conceptualized as a new subsystem within the hospital; and the staff advisor's work with the parents can also be conceptualized as a new role which had to be made more effective.

How was the Parents Association implemented? Rothman specifies two basic models (with many variations) which can be utilized for the implementation of any given innovative project:[3]

(a) Spontaneous Contagion Model
P -- Partial Target System -- General Target System

(b) P -- Partial Target System -- Decision Making Unit -- General Target System

In (a) the practitioner (P) introduces the innovation to only a sample of the target population, who, in turn, introduces the innovation directly to the total population. In (b), there is an agent or transfer mechanism through which the innovation is spread to the total population.

For this particular project, the transfer mechanism existed at the outset so that the implementation process can be diagrammed as follows:

(c) Decision Making Unit -- P -- Partial Target System -- General Target System

In other words, before the staff advisor or P (practitioner) was able to act he had to first obtain approval from key individuals within his organization. From January to June 1976, the Parents Association followed the process of model (c). Now that the parents have discovered, however, that they no longer have access to certain resources and the power to pry loose some of these resources from either the educational or the health establishments, they recognized that they need another decision-making unit* which could give them the clout to obtain what they need. From a long-run perspective, model (c) has to

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*The decision-making unit (#2) will probably be one of the new five regional councils created by the Metropolitan Placement Unit, under the auspices of New York State Department of Mental Hygiene and Mental Retardation; each council will be responsible for the planning and implementation of community-based services in its respective areas.

be converted to model (d):

(d) Decision Making Unit (31) -- P -- Partial Target System -- Decision Making Unit (#2) General Target System

Recommendation 1.

This project has demonstrated that a practitioner must not assume that once a self-help group receives authorization to come into existence that the group does not have to renew that authorization from either the same auspices or from an entirely different source. In this study, the lack of resources available after June 1976 made it necessary for the participants to consider an entirely new and different decision-making unit for authorization as well as renewed authorization from the hospital.

Facilitating Factors

One of the primary reasons why the Parents Association did not have to expend too much energy justifying and defending its right to existence was that the facilitating factors outweighed the inhibiting factors. The following represents only a partial list of facilitating factors:

a. Personal Factors. Based on the respect for, and the predictability of the staff advisor's performance as a Social Worker and Coordinator over a two year period (1973-1975), the hospital administration was willing to take the 'gamble' with the creation of a Parents Association. It can be considered a 'gamble' because any innovation, particularly an innovation which involves a key organizational feature (e.g., decision-making process), may generate more change than the organization has initially bargained for. What tipped the scales in favor of the project was in part the hospital's respect for the staff advisor's past performance as it pertained to community relations.

b. Organizational Factors. The fact that the Developmental Center's funding agency approved of, and encouraged, the staff advisor's efforts to work with the parents to obtain a vital service for their children was a significant inducement for the hospital administration to 'go along' with the idea of a Parents Association. The fact that the hospital was already sponsoring parent groups within its psychiatry and drug programs also minimized any anxiety the

administration might have had regarding a parents auxiliary association attached to the Developmental Center.

c. Client Factors. As the Developmental Center's Social Worker, the staff advisor appreciated the fact that many parents of handicapped children suffer from a sense of impotence because they, unlike parents of healthy children, have so little power to alter their children's chances for growth and development. It was the parents' need to exert some control over their children's present and future welfare that outweighed the 'costs' of participation (e.g., being away from their families so they could attend meetings; arguments with spouses, etc.).

d. Community Factors. The history of services for the mentally retarded has been basically the history of parents of the retarded fighting for services for their children. In 1975, the concepts of normalization and continuum of care were already accepted as conventional wisdom by many in the human service establishment. The parents, therefore, did not have to argue with, convince, or cajole professionals/administrators of the merits of specialized preschool programs for developmentally handicapped children. This acceptance by the professional community of the need

for specialized services outweighed whatever indifference or resistance might have existed in the community at the time of implementation.

Recommendation 2.

An assessment of the facilitating factors has to be combined with an assessment of existing resources. A professional can make a critical contribution to a local self-help group at a time when resources are available. To put it another way: a professional can assist the parents in the short-run to learn how to quickly compete/negotiate for "part of the pie." However, if and when the resources begin to contract, a local, organizational-based self-help group may no longer possess the capacity and leverage to reach its objectives. It will have to transform itself and the professional will have to shift to a different set of practice principles.

It may be necessary, for example, for the Parents Association to sever its formal ties with the hospital so that it can, perhaps, assume a social action posture (and hire a lawyer!); and, if necessary, to recruit "friends," irrespective of their auspices, over and beyond local

community boundaries. The job of the staff advisor, then, under these circumstances, would require consummate skill because he must not only 'enable' the parents to 'leave' the organization which offered them succor and sanctuary; but he must also do it in such a way that the parents as well as the hospital administration consider and experience the exodus of the parents from the hospital as a necessary but positive change.

Creating A New Role

Rothman describes four modes by which a practitioner can alter, modify or create a new role for himself. They are:[4]

1. Agreement -→ exercising the role
2. Environmental legitimitation or support --→ agreement --→ exercising the role
3. Demonstrating the role --→ agreement --→ expanded exercise of the role
4. Agreement --→ demonstrating the role --→ expanded exercise of the role

For the implementation of the Parents Association, mode #3 was applicable. The staff advisor demonstrated that he could conduct a community meeting (which required technical

knowledge as well as personal confidence); he, then secured--by initiating and orchestrating a variety of contacts--agreement from the hospital's administration to act as a staff advisor to the Parents Association.

The staff advisor wanted the parents to maintain a "low profile" at the beginning of the implementation process. His practice principle at this particular stage was that a "good beginning would help to assure a good outcome." This is not to imply that the staff advisor was either omniscient and omnipresent or that the parents were totally inactive. What it does mean is that a practitioner must decide how visible he wants the self-help group to be to the formal organization and when this visibility should occur. In this applied-research project,* the staff advisor felt that the visibility of the parents required two pre-conditions: (a) the agreement for the creation of the Parents Association had to be <u>firmly established</u> between the practitioner and his superordinates; and, (b) the

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*The phrase "applied-research project" is being used as a synonym for "demonstration project," i.e., a project which demonstrates, but does not verify, principles in action.

parents had to establish some organizational structure, no matter how elementary, as well as a stabilized attendance pattern. The basic assumption underlying these two pre-conditions was that a practitioner must not (within his control) create any "excuses" or "ammunition" which the organization can use to discredit the innovation at its point of take-off: which was the most vulnerable point for the Parents Association.

Recommendation 3a.

This discussion on 'securing a firm initial agreement' leads to another recommendation: A practitioner cannot assume that he does not have to "renew" the initial agreement from time-to-time. We can raise the question as to whether the staff advisor experienced as much role strain as he did with certain administrators because he failed to obtain the initial agreement in more formal terms. Rothman does not specify under what conditions a practitioner should be satisfied with (say) a "hand-shake" with his superordinates or when a practitioner should (or must!) request the agreement in writing. As a rule of thumb, a practitioner stands more on terra firma whenever he can

support his actions with a written statement; a verbal or informal agreement is not only open to more interpretations than a written statement but there even may be denial that an agreement ever existed.

Recommendation 3b.

It may be only possible, and sufficient, to get only a hand-shake and a verbal statement (i.e., made, of course, "on the record") as a basis for an initial agreement. The organization may not be inclined to commit itself in writing to something that could prove to be advantageous at the moment but controversial and deleterious later. What a practitioner must recognize and appreciate is the fact that circumstances (i.e., contextual factors) change so that the "initial agreement," no matter how it was made (informal or formal), could acquire different meaning to the contracting participants. For example, the hospital administration's respect for the staff advisor's performance remained the same throughout the course of the project; nonetheless, as soon as the administrators felt that the parents expected the hospital to give rather than to receive resources, the staff advisor was the person who

received warnings about making too many demands. The danger in this type of situation is that the practitioner may become angry because he believes that his organization has acted dishonestly when, in truth, the organization has demonstrated a 'failure of nerve' due to changing circumstances (e.g., parents looking to the hospital as a source for resources rather than bringing new resources into the hsopital). A practitioner shows his mettle when he is under attack but behaves like a statesman because he understands the source of the organizational anxiety.

New Issues and New Contexts

Every study inevitably brings to the surface new questions and issues or old issues but within new contexts. The purpose of identifying such new questions and new contexts is to precipitate further discussion and hypothesis formulation. Hopefully, other applied-research projects will enlarge and add further substance to the discussion.

1. What about the power factor? Power may be defined as the capacity of actor A to get actor B to do what A wants; or to prevent B from acting. The staff advisor and

the parents were ethically repelled by the principle 'might makes right.' But at the same time they were also aware that the principle 'right makes might,' though ethically laudable, was not always effective since organizations rarely respond only to the merits of a request.

The staff advisor frequently did not know how much power either he or the parents possessed vis a vis the hospital or the Board of Education; and "how" and "when" they could wield the power that they did possess. An accurate diagnosis of the power factor can be as problematic and demanding as a case-work psychosocial diagnosis. The overall strategy from January to June 1976 was to "box-in" the hospital and the Board of Education so that any given administrator would find it difficult (due to public relations embarrassment, legal constraints, personal guilt, etc.) to turn down a request made by the Parents Association.

The use of power and the use of locality development as a community organization intervention were not mutually exclusive. Locality development rhetoric is deceptive because it gives the impression that considerations of power do not and should not exist; and when it does

exist, it must be eliminated because power can only corrupt the democratic process. The evidence of this study suggested, to the contrary, that when the power factor was acknowledged and applied judiciously, locality development was politically effective.

Because the staff advisor was often uncertain as to what the calculus of power was at any given time, his only means of 'finding out' was to 'test' the organization. The test would consist of purposely and carefully eliciting a reaction from the organization and then analyzing the reaction for its duration, intensity and content. For example, the staff advisor discovered that the hospital administration was complacent whenever the staff advisor would give in-house memoes to the parents. However, there was always a loud shriek whenever the staff advisor attempted to use the Parents Association as an ally to "do battle" against other hospital departments. Each reaction from the hospital was a basis for a rough estimation of what the parents and the staff advisor could or could not do and what the hospital could or could not do.

It was almost as if the staff advisor, whose objective was the creation of a harmonious atmosphere, was playing a piano: striking a key to hear whether the key produced a harmonious or discordant note; if it were harmonious, then the key (i.e., or action) could be tried again; if the note were discordant, another key would be tried or the same key would be struck at another time.

Since no situation in the human relations field is absolutely clear and unambiguous, a practitioner has to ask himself: "Am I prepared to risk testing my employer to ascertain how much power is possessed by the self-help group?"

2. Process and Task Goals. In the 1960's it was rather fashionable to criticize the concept of the practitioner as an enabler because democracy as a political concept was considered nothing more than a myth. Urban problems were also viewed as too complex and intractable for resolution by local or neighborhood groups.

In the 1970's, however, skepticism over the merits of macroplanning and centralized structures for either the planning or the delivery of health/social/educational services, has reawakened interest in decentralization and

community/locality development. As this study has demonstrated, locality development can effectively accomplish both task (e.g., obtaining a tangible objective such as a preschool program) and process (e.g., helping parents learn organizational skills) goals.

Task and process goals are both equally necessary for a community organization intervention; both type of goals reinforce one another. For example, the Parents Association has and still is surviving because it has not forgotten its task goal; and, equally important, it has not forgotten that they could not continue to exist organizationally unless they learned how to solve problems together; how to live with ambiguous situations; and, how to acquire 10% today so that tomorrow or the day after they might acquire 20% or 30%.

Is it possible that locality development, as a method which utilizes task and process goals, is less conservative than a methodology which is insensitive and indifferent to the long-range contribution (intellectual, social, emotional) it can make to its participants?

3. Confidentiality. In a clinical relationship, confidentiality is considered sacrosanct because without

it a client would refuse to enter into a helping relationship. Confidentiality, however, becomes less of a burning issue when people bring issues into the public domain. In this applied-research study, the issue of confidentiality did rear its problematic head on occasion. First, the staff advisor expected the parents to keep certain information quiet because he was concerned that the hospital administration might perceive him as an "agency insurgent." Secondly, a few of the parents wanted their affiliation with the Parents Association to be kept quiet because they did not want to jeopardize their children's chances of getting services from either within or outside of the hospital.

The staff advisor made a conscious effort not to divulge (or to single-out) the names of parents who were responsible for any given decision. In other words, what was important for the hospital administration was the decision itself as well as the fact that the decision was endorsed by the Parents Association, not the name of this or that parent who instigated the decision. The parents also kept their word to respect the staff advisor's request for confidentiality.

Can we conclude that in a community organization intervention the social worker has as much to lose as the program participants whenever there is a breach in confidentiality?

4. The norm of reciprocity. The addition and subtraction of who owes what to whom was, to paraphrase an old political aphorism, "openly discussed and openly arrived at" throughout the study. It was the basis for the agreement between the parents and the hospital administration. The parents as well as the hospital recognized that they both shared the desire and "thirst" for resources (i.e., funds, equipment, staff, and publicity). This appreciation by the parents for the hospital's need for resources was a critical and significant factor in the acceptance of the Parents Association by the hospital. The hospital administration was "turned-on" by the parents willingness to acquire resources for the hospital.

An interesting "what if?" question presents itself. What if the parents were attached to (say) a community settlement house which assigned a staff member to the self-help group. In such a situation, should the staff member choose a social action model rather than locality

development to get the hospital to assist the parents? A gedank experiment, that is, a "what if" situation, can only suggest possibilities since it poses a question after the fact. The fact that the norm of reciprocity was a basis for a traditional, non-community organization type of organization such as a hospital to accept the Parents Association under its roof would seem to indicate that locality development rather than a social action model would be the method of choice for our settlement house staff member. Because a social action model, with its predilection for confrontation, dramatic demonstrations, and intimidation of the "opposition," might have succeeded in getting all parties involved "angry" without winning anything (i.e., resources) for anyone; more importantly, such an approach, if utilized initially by the settlement house staff worker, could have had the effect of forcing extraneous factors (e.g., saving face, interorganizational friction, etc.) into the situation so that the issue of the need for a specialized preschool program becomes only an incidental issue rather than the primary issue. Consequently, locality development may be an effective method not only for working within the system but equally

effective for working outside of the system.

5. Who does what? How did the staff advisor decide when the parents needed his guidance and consultation? One of the staff advisor's practice principles was a popular medical principle, namely, "first, do no harm." In other words, before a physician prescribes a medication he has to have some degree of certainty that the cure is not worse than the illness. The staff advisor adhered to this principle by assuming that the parents had the capacity to competently achieve any given task; only after the staff advisor observed that the parents needed assistance did he offer suggestions and/or do it (i.e., the task) himself with the parents as spectators. Throughout the course of the project, the staff advisor was extremely active because as soon as the parents learned one set of skills (e.g., how to conduct a business meeting, how to arrange a visit to another agency, etc.), changing circumstances forced them to learn new skills (e.g., how to negotiate with administrators, how to cope with television publicity and newspaper interviews, etc.).

There was, however, one activity with which the

parents needed only minimal assistance so that the staff advisor's involvement was reduced to a minimum. The activity was fund raising through flea markets. Parents made all the organizational contacts, collected all the merchandise, rotated themselves on the day of the flea market, and did all the necessary bookkeeping. The staff advisor was always available when and if the parents needed his assistance; but availability was a passive form of assistance. After the first and second flea markets, the staff advisor informed the association that all he wanted to know was on which day a flea market had been scheduled; he did not need to know how they were planning for it.

The staff advisor's involvement, i.e., his degree of "enabling," was also predicated on the parents doing no harm to themselves or to the hospital (though both were inextricably intertwined!). As soon as the staff advisor felt assured that the Parents Association, particularly the chairperson, understood and accepted the concept of the norm of reciprocity, he felt that his role as enabler (active) could be changed to that of consultant (passive). Once again, locality development rhetoric gives the false

impression that the enabler exerts minimal control throughout the process. This study has indicated that without strong control over the process by the staff advisor at the beginning of the process, the Parents Association would (in retrospect) certainly have met with failure. In the same way that self-determination and autonomy are not virtues in of themselves, a practitioner who wants to assist a self-help group has to ask himself: "Am I prepared to assume some responsibility for the growth and development of the self-help group?" If the answer is "yes," then he must be willing, ready, and prepared to exert some control over the growth process rather than letting things happen fortuitously or letting the parents do what they want no matter what the consequences. What is at stake is either success or failure. Parents who desperately need specialized services for their handicapped children cannot afford failure!

Notes

1. Jack Rothman, John L. Erlich, and Joseph G. Theresa, Promoting Innovation and Change in Organizations and Communities: A Planning Manual (New York: John Wiley and Sons, Inc., 1976), pp. 23-59.

2. Ibid., pp. 134-169.

3. Ibid., p. 29.

4. Ibid., pp. 143-148.

A P P E N D I C E S

APPENDIX A

PROPOSAL SUBMITTED TO HOSPITAL ADMINISTRATORS

I. WHAT IS THE NEED?

It is estimated that there are 8,416 retarded individuals in our community (Community Planning Districts 13 and 15). Of these individuals, it is projected that there are 627 retarded children under the age of five.*

In the local community there are no existing infant or pre-school training programs. The Child Developmental Center is forced to refer its pre-school children (more than 50% of our case load) to programs outside of the community. We know from experience that an inaccessible service is in fact no service. On May 14, 1975 the staff advisor informed Dr. June Christmas, Commissioner of Mental Health and Mental Retardation, at her "Spring Meeting" here at the hospital that a number one priority for the retarded and developmentally disabled child in Coney Island are pre-school programs.

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*From the 1974-1975, 1975-1976 Bureau of Mental Retardation Borough-Wide Planning Report.

II. AN AUXILIARY PARENTS' ASSOCIATION

In the field of mental retardation there is a rich tradition of parent participation to obtain services for their children. This tradition has taken place not only in the United States but also in Europe, South America, and Canada. Parents of the retarded have to convince, through responsible voluntary organization, various constituencies that the provision of services, particularly education, are needed. Education is the primary therapy for the retarded child!

Beginning in September 1975, the staff advisor would like to test <u>feasibility</u> of organizing the parents of the children Developmental Center services into an association whose primary goal would be to obtain pre-school programs within our community. This type of an association would involve contacts with other community agencies such as Day Care Centers, Head Start, Public Schools, etc. (On May 1, 1975, the staff advisor invited personnel from these agencies to a meeting here at the hospital. Their presence was an indication of their keen interest and concern.)

The staff advisor's role with this association would

be that of enabler (to help parents identify their needs and the capacity to solve their problems) and planner (to help evaluate the pros and cons of alternatives and for recommending a course of action to those who make the decisions).

An auxiliary parents' association can only be successful if it functions within an "encouraging environment." Since November 1973, the Developmental Center has developed a good working relationship with community social service and health agencies: The Center's staff believes that it is perceived positively by other community agencies.

To help create a more effective and viable constituency for our parents' association, it would be necessary to form a coalition of professionals (and parents!) to create guidelines for the organization and allocation of resources for preschool programs.

III. MONITORING AND EVALUATION

As soon as the process of building an auxiliary association of parents begins, there will be monitoring

procedures instituted to determine whether goals are being reached.

Parents of the retarded child need each other for comfort and support. But, more importantly, they need to join with each other, as they have done successfully in the past, to obtain needed services so that their children can live at home and develop into productive citizens. The Developmental Center as well as the hospital have the opportunity to provide these parents with encouragement and expertise.

APPENDIX B

INSTRUCTIONS FOR THE USE OF THE DAILY PLANNER AND THREE SAMPLE COPIES

The Daily Planner form has been developed as an aid to the staff advisor in keeping a record of all activities engaged in while developing a preschool program for retarded children. The form was designed to be used in scheduling activities to be done, and when the activity, telephone call, meeting or correspondence is completed it could be checked off as having been completed.

The Daily Planner should be maintained as a record of each day's activity; that is, each action of the staff advisor's activities should be recorded daily on the day the activity was planned or completed rather than completed as a weekly summary.

Activities to Do

This section can be used to record tasks to be done in developing the new service. When scheduling or planning activities the activities to be accomplished can be recorded and completion indicated with a check (✓).

Telephone Calls

In planning activities for the day, the name, agency (organization) and telephone number of the person to whom the call is directed can be entered. Upon completion of the call a line can be drawn through to indicate completion. The Planner will thus become a record of telephone activity which the staff advisor can use to establish both the amount and nature of activities involved in developing or expanding services.

Meetings/Conferences

Like the recording of telephone calls, meetings,

conferences, or any other group sessions should be identified. The nature or purpose of the meeting, in brief, should be stated and where possible the number of people attending should be listed.

Correspondence

Letters, memos and other correspondence would be identified and listed on the staff advisor's planner. The title of the person and agency (organization) should also be entered on the form.

Expenses

All out-of-pocket expenses of the staff advisor for which the staff advisor is to be reimbursed should be listed in this section.

Staff advisor's out-of-pocket expenses in connection with the Project could include: telephone calls, local and long distance; local car fare and mileage; postage; stationery; audio-visual equipment rental.

COMMENTS/PROBLEMS/ACCOMPLISHMENTS

This section is to be used for comments as well as a summary of what accomplishments have been made toward the goal of developing the new service.

Activities of Other People/Organizations

In the process of developing this new service the staff advisor will more than likely engage the actions of other people or agencies. He should record this activity in order to identify the full extent of actions necessary to creating this new service. The following information should be entered on the form:

The person's (or agency) name and position (job title).

Whether the person is a volunteer or being paid by an agency while engaged in the work of developing service.

The nature of the activity and involvement.

The motivation of the person (or people) involved is an important item to be entered. This information can be ascertained either by obtaining a direct statement from the person or by inference.

DAILY PLANNER 1

ADVOCATE Staff Advisor

COMMUNITY in Brooklyn, New York DATE(S) 2/11/76 (Month Day(s))

ACTIVITIES TO DO	COMPLETED (✓)
1. Meeting today with staff from Agency X to discuss "preschool" programs 1:30 p.m. Staff Advisor, Medical Director and Mrs. C. (parent) will attend	✓
2. Administrator called unscheduled meeting at 9:30 a.m. Staff Advisor, Medical Director, Chief, Pediatrics, Chief, Rehab. Medicine, Adm. Ass't. Rehab. Medicine.	✓
3. Schedule visit to Brookdale Hospital to see preschool program.	

TELEPHONE CALLS (specify title of person and agency)	MEETINGS/CONFERENCES (specify number of people, purpose)
Mrs. P. called staff advisor a. Staff advisor asked her to remove flea market items from his office b. That the hospital will provide space for the preschool program	*Two (2) meetings 1. scheduled at 1:30 p.m. 2. unscheduled at 9:30 a.m.

DAILY PLANNER 1

TELEPHONE CALLS
(continued)

c. That Mrs. P. should think about meeting with the Chief of Pediatrics without staff advisor.

CORRESPONDENCE (specify title of person and agency)	EXPENSES Item	Amount
None	None	

COMMENTS/PROBLEMS/ACCOMPLISHMENTS

*Unscheduled meeting--Staff advisor briefs the group on the efforts of the Parents Association. Chief, Rehab. Medicine, promises to provide space for any prospective preschool program.

Scheduled Meeting--Mrs. C. agreed with the staff advisor that the staff from Agency X were most reluctant to include parents in the decision-making process of Agency X's preschool program.

DAILY PLANNER 1

ADVOCATE Staff Advisor 2/11/76

COMMENTS/NOTES/ACCOMPLISHMENTS

ACTIVITIES OF OTHER PEOPLE/ORGANIZATIONS

Person-Position/Organization	Paid	Volunteer
Agency X	✓	

Activity-Involvement	Motivation
Wanted to meet parents of handicapped preschool children.	They received a grant for a preschool program and they need children for the program

COMMENTS/PROBLEMS/ACCOMPLISHMENTS

Problem--Agency X is a large, established agency in the field of mental retardation. The meeting was tense and unproductive. Staff advisor will consult with hospital Administrator, Senior Consultant from The Bureau of Mental Retardation and the Parents Association.

DAILY PLANNER 2

ADVOCATE Staff Advisor

COMMUNITY in Brooklyn, N. Y. DATE(S) 4/20/76
Month Day(s)

ACTIVITIES TO DO	COMPLETED (✓)
9:30 a.m. meeting with Administrator to review draft letter of agreement between Board of Education and hospital.	✓ 9:30 a.m.- 10:00 a.m.
10:00 a.m. to meet with Administrator and Executive Director	✓ 10-10:30 a.m.

TELEPHONE CALLS (specify title of person and agency)	MEETINGS/CONFERENCES (specify number of people, purpose)
Call Mrs. P (chairperson) to tell her that program will probably be on the 9th, not the 3rd floor. She was angry because she felt 3rd floor had more advantages. She said that the parents plan to discuss it further.	

CORRESPONDENCE (specify title of person and agency)	EXPENSES Item	Amount

COMMENTS/PROBLEMS/ACCOMPLISHMENTS

The Executive Director liked the letter but added that the Bd. of Ed. teacher must abide by all hospital rules. He was apologetic that the hospital was not able to subsidize "cookies and milk" for the children.

DAILY PLANNER 3

ADVOCATE Staff Advisor

COMMUNITY in Brooklyn, N.Y. DATE(S) May 7, 1976
Month Day(s)

ACTIVITIES TO DO	COMPLETED (✓)
Request meeting with Social Services Director to discuss composition of Advisory Comm. for preschool program	✓ 4:15 p.m.

TELEPHONE CALLS (specify title of person and agency)	MEETINGS/CONFERENCES (specify number of people, purpose
*Mrs. P. called (Chairperson)	

CORRESPONDENCE (specify title of person and agency)	EXPENSES Item	Amount
Letter will be signed by Executive Director and later signed by the Dir. of the Bureau of CRMD. (The letter did not have to be reviewed by the Health & Hospital Corp.)		

COMMENTS/PROBLEMS/ACCOMPLISHMENTS

*Mrs. P. has been in touch with the local Head Start Psychologist, who informed her that he wants a mtg. with the parents and staff advisor to discuss accepting developmentally handicapped children in the Head Start program. Mrs. P. is skeptical because their intake requirements are still restrictive.

DAILY PLANNER 3

ADVOCATE Staff Advisor May 7, 1976

COMMENTS/NOTES/ACCOMPLISHMENTS

ACTIVITIES OF OTHER PEOPLE/ORGANIZATIONS

Person-Position/Organization	Paid	Volunteer
Scheduled meeting May 24 at 3:00 p.m. at the hospital to discuss developmentally handicapped children and Head Start. (The mtg. was scheduled by Mrs. P., chairperson.)	✓	

COMMENTS/PROBLEMS/ACCOMPLISHMENTS

APPENDIX C

FORM USED FOR RECORDING MEETINGS

Date of Recording_____ Date of Meeting_____

Name of Nucleus _____ Person Recording_____

Occasion_____ Place_____
(Regular or Special Meeting, Work Project, etc.) (Location)

Time of Beginning _____ Time of Ending_____

Citizens Present:

Name	Occupation	Representing Special Interest?
1.		
2.		
3.		
4.		
5.		
6.		
7.		

Helpers Present:

Staff Advisor _____

Resource Discussants _____

Visitors _____

Record of Meeting

A. Matters Under Discussion

B. Decisions Reached

C. Matters Deferred

D. Next Meeting (Date, Time, Place)

E. Significant Side Conversations
(before, during, and after meeting)

APPENDIX D

SCALE TO MEASURE COMMUNITY PARTICIPATION

Name _____

Address _____

Age _____ Education _____

Occupation _____

Name of Organization	1. Member*	2. Attendance	3. Financial Contributions	4. Member of Committees (Not Name)	5. Office Held
1.					
2.					
3.					
4.					
5.					

*L = local group N = local unit of a state or national organization.

"Social Participation Scale, 1952 Edition," F. Stuart Chapin, University of Minnesota, Delbert C. Miller, Handbook of Research Design and Social Measurement (New York: David McKay Company, Inc., 1970), p. 291.

APPENDIX E

SCALE TO MEASURE ALIENATION

NAME _____

ADDRESS _____

1. _____ I think we have adequate means for preventing run-away inflation.
   _____ There's very little we can do to keep prices from going higher.

2. _____ Persons like myself have little chance of protecting our personal interests when they conflict with those of strong pressure groups.
   _____ I feel that we have adequate ways of coping with pressure groups.

3. _____ A lasting world peace can be achieved by those of us who work toward it.
   _____ There's very little we can do to bring about a permanent world peace.

4. _____ There's very little persons like myself can do to improve world opinion of the United States.
   _____ I think each of us can do a great deal to improve world opinion of the United States.

5. _____ This world is run by the few people in power, and there is not much the little guy can do about it.
   _____ The average citizen can have an influence on government decisions.

6. _____ It is only wishful thinking to believe that one can really influence what happens in society at large.
   _____ People like me can change the course of world

events if we make ourselves heard.

7. _____ More and more, I feel helpless in the face of what's happening in the world today.
_____ I sometimes feel personally to blame for the sad state of affairs in our government.

Neal and Seeman Powerlessness Scale

"The authors define powerlessness as 'low expectancies for control of events' as lack of control over the political system, the industrial economy, and international affairs. Basically measures the subjectively held probabilities that the outcome of political and economic events cannot be adequately controlled by oneself or collectively by persons like oneself."

--from Delbert C. Miller, Handbook of Research Design and Social Measurement (New York: David McKay Company, Inc., 1970), p. 318.

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