

Dec 1963

I Mental retardation, like headache, is a symptom not a diagnosis.

II Techniques are now available in the biological sciences, in education, in the social and behavioral sciences that make it possible to diagnose, and assess a child's total abilities and disabilities as well as ^{the} influence of the environment on his development. It is possible, therefore, to differentiate between conditions such as the following: Emotional disturbance, cultural deprivation, neurological and sensory handicaps resulting in aphasia, dyslexia and related disorders, congenital or acquired deformities resulting in delayed development, Chromosome and Chemical anomalies associated with low learning capacity.

III. Public and private money is being made available for care, study, education and research in the field of normal and abnormal human development.

IV. There is a growing feeling among parents and professional staffs working with handicapped children that a great many of these children should be taken care of in their homes and not in large remotely located custodial institutions.

V. Private practicing pediatricians and other physicians are the first to see a handicapped child or the first to be consulted when a parent suspects a delay or defect in development.

VI. Some of the common errors made by physicians:

- 1) Prediction on a young infant, such as "He cannot survive long!" "He will never walk"; "He will never develop beyond four or five years of age" Such predictions are repeatedly refuted.
- 2) Do not increase the "Hurt" with such remarks as, "He is no good, put him away", "He is wasting your time and mine", "I can't do anything for him. You need not bring him in any more"; "He is hurting the rest of the family, remove him."
- 3) False re-assurance such as, "He will out-grow it".

VII. What can be done?

- 1) The child and the parents are entitled to have an accurate diagnosis whenever possible.
- 2) They are entitled to an assessment of his total abilities over a long enough period of time (this may mean observation over weeks, months or years) for the staff and the parents to be satisfied that his potential is known.
- 3) Parents need your counsel and support as much as for a normal child plus the problem produced by the handicap.
- 4) The child needs the same medical attention as any other baby. He is a human being.

1963

A COMPREHENSIVE COMMUNITY ORGANIZATION PLAN AROUND THE
MENTALLY RETARDED

BACKGROUND AND HISTORY: The visit of Mr. and Mrs. R. Sargent Shriver, Jr., to San Francisco and to Aid Retarded Children triggered a chain of events which led to the idea that San Francisco might be an ideal location in which to do a demonstration of total services to mentally retarded children and adults, thus showing what is possible to accomplish in the light of present knowledge in preventing, ameliorating and coping with the problem in all its aspects.

An ad hoc committee held several informal meetings to consider the purposes to be served by such a demonstration and the shape it might take. This group included Irving Wiener, Dr. David De Marche, Dr. Robert Kimmich, Edgar Pye, Peter Haas, and Margarete Connolly. They met with Philip Schafer, Western Regional Director of the U. S. Rehabilitation Administration as a consultant.

THE GOAL: The basic goal would be a massive attempt to use every resource, in a concentrated, all-out push, to provide across-the-board services to the retarded and their families and thus demonstrate that by providing preventive services, early diagnosis and family counseling with appropriate referral, education and training, legal and social protection, recreation and residential facilities, the tide of demand for institutional care could be reversed and millions of dollars of tax dollars saved and/or diverted to local use.

PRINCIPLES: The principles considered were that all the professional and technical expertise of San Francisco would need to be marshalled; that since the assumption in a "demonstration" is that what is sound and useable will be built permanently into the social structure, all of those who influence change in the community would be involved in the decision-making process; that the time factor is a crucial one if this is to be a demonstration of total services, since these services would need to be concurrent if they are to demonstrate a net work of totality.

METHOD: There probably would be three phases in the program:

- I. Pre-planning, which could begin almost at once with a small grant of funds probably available through the U. S. Rehabilitation Administration. This would lead to the
- II. Planning Phase during which time a so-called "Master Plan" would be developed and simultaneously some phases of the project itself would begin (i.e. the Information and Referral Service of the S. F. Community Mental Health Service, by consensus, has priority for development). The stage would be set in helping a great number of agencies enter the
- III. Project phase:
Appropriate agencies would apply for grants to extend existing services or develop new services for the mentally retarded and their families.

SPONSORING ORGANIZATION -

Several alternatives have been suggested:

1. An operating Board of Directors appointed by any one of the following organizations:
 - Aid Retarded Children
 - S. F. Coordinating Council on Mental Retardation
 - S. F. United Community Fund
2. An operating Board of Directors appointed jointly by Aid Retarded Children, the S. F. Coordinating Council on Mental Retardation and the United Community Fund.
3. Other?

Membership on this Board could be spelled out to assure representation from certain areas of community life. It is possible to develop such a Board by agreement or by incorporation of a new entity, but only one organization would hold responsibility for fiscal management of the project.

FACT SHEET ON LOCAL PLANNING FOR CHILDREN WITH DEFECTS.

I. Centers are now available for:

- 1) Medical Diagnosis
- 2) Total assessment of the child's abilities and disabilities
- 3) Social evaluation of the home and environment and determination of the effect of this impact on the child and the child or the family
- 4) Counseling
- 5) Re-evaluation

Child needs more than a medical evaluation - he lives 24 hrs a day - 7 days a week - for this in his community. The community need to make provision for the handicapped child at local levels

II. Resources in the community:

- 1) Private physicians
- 2) Public Health personnel, CCS, Maternal and Child Health, Nurses
- 3) Special Education
- 4) Religious Organizations
- 5) Voluntary Health Agencies
- 6) Local Clubs and organizations as lodges, PTA, Business and professional Clubs

Druggists

III. Approaches to inter-agency communication and co-operation

- 1) Start something, somewhere even if it is merely getting to know a child who is handicapped
- 2) Start some recreation for the handicapped. This is a universally neglected area. Show the film "Recreation for the Handicapped" which may be obtained from (A) Communication Dept. Stanford Univ. Palo Alto, Calif. or from (B) Mrs. Morris Pomeroy, Recreation for the Handicapped, Flieshacher Pool Great Highway, San Francisco.
- 3) Review Mrs. Pomeroy's book on the handicapped when it appears next Spring.
- 4) Get suggestions from the State Consultant, Edgar Pye, 3330 Geary Blvd San Francisco, Cal.
- 5) Encourage a Church group or groups to start a Sunday School Class for handicapped children, or day classes or a day care center.
- 6) Organize and train some teen-age baby sitters for the handicapped
- 7) Interest one or more physicians

*woman physician
pediatrician
psychiatrist
voc. training in orthopedics*

*from Co Med Society
St Paul's
Oct 1963*

Children's Attitude

*How attack = Educ { med -
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Med Schools
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Financing = Ins. C.C.S. - Shurt Doyle
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Religion =*

How can you proceed to mobilize a community to meet the needs of children with defects

1963

A CONTRIBUTION OF VETERANS ADMINISTRATION HOSPITALS TO PEDIATRICS

By

H. E. Thelander, M. D.

For some time, I have felt a desire to give credit to the Veterans Administration Hospitals for the contribution to Pediatrics that has resulted from my own experience as a consultant to the Hospitals.

Twelve years ago when I was Chief of Pediatrics at Children's Hospital in San Francisco, I was asked by the United Cerebral Palsy Association to start a Pre-Nursery School Program for children with cerebral palsy. Public schools, by law, in California are responsible for the education of children with cerebral palsy from three years on. Since the children seen, therefore, would be the young group, and a program was new, I made a few stipulations such as follows:

1. A rigid diagnosis at that early age should not be demanded.
2. The upper age limit of three years should not be adhered to, as some of the children were very stunted in their development and would not be eligible for a public school.
3. Rigid county lines should not be required; at least not until the neighboring counties had developed programs.
4. The children should return for follow-up indefinitely, so that we would know the outcome.

Prior to opening the Program, I visited the Institute of Dr. Howard Rusk in New York, Mrs. Tracy's Nursery School for the Deaf in Los Angeles, and several other places. However, I was influenced most by my experience with the Veterans Administration Hospitals and their Rehabilitation Programs as I saw them at the various Hospitals in the Western Area. The Program, as established, is definitely an adaptation to children with handicaps of the techniques I have seen on the visits of the Veterans Hospitals.

Not long after the opening of the Nursery School, the Crippled Children Services of the State Board of Health established a Neurological Diagnostic Clinic in connection with the program, and later the March of Dimes asked us to conduct a Birth Defects Center. When the Academy of Pediatrics established a section on child development, the name of our activity was broadened to "Child Development Center".

A pediatrician is in charge of the Center. The other specialties and sub-specialties in medicine are available on a consulting basis for both diagnosis and treatment. The hospital laboratory is well equipped for diagnostic procedures, including chromosomal studies. The non-medical staff includes, (1) a social worker, (2) a psychologist, (3) a nursery school teacher, (4) a speech audiologist, (5) a physiotherapist, (6) an occupational therapist, (7) secretaries and volunteers. Each child referred to the Center gets not only a medical study, but the child gets a careful assessment of all his abilities and his handicaps, and the parents at home are fully evaluated. The object of the Nursery School and the associated therapies is to prepare each child for the next experience in the community. The Public Health Nurses are used to assess the homes and the school facilities. Frequent conferences are held. To these conferences, in addition to the medical and ancillary staff of the Center, teachers, visiting nurses, and referring doctors are invited. The children are re-evaluated at intervals as indicated, and the door is open at all times for parents to return if a crisis threatens or occurs.

One of our discoveries has been that the communities are organized, both for financing and for services, around disease categories rather than around children and their needs; that is, the Deaf School will not accommodate a deaf retarded child, the Cerebral Palsy School cannot meet the needs of a blind cerebral palsied child, and so on, ad infinitum. There are problems of aphasia, dyslexia, hyperkinesis, and retardation associated with practically every major disease category. A great deal of effort is going on now in attempts to change the old concepts as they have developed in the community, and to make the continuation of the care of the child more realistic.

Within the last five or six years, child development centers have been organized in many medical schools and pediatric hospitals across the country. It is also interesting to learn that these are now adding nursery schools. In fact, Dr. Howard Rusk has just started a

a nursery school in his activity. Our work is now considered as pioneer work in the field of child development as it pertains to children born with or acquiring imperfections. Pediatricians are turning to work with the chronically handicapped child now. This is appropriate, since many of the acute infections have been controlled either by immunization or therapy. The problems of the chronically handicapped child are now being attacked as the infectious diseases were by preventive measures, repair, rehabilitation, and placement.

As our children reach adolescence and adult life, we cannot help but deplore the fact that this type of total service to patients is not more generally available to adults, and that this concept has not been taken over by all physicians. I would like to suggest that the physicians in the Veterans Administration Hospitals help sell the idea to internists and surgeons. I think they have been entirely too modest in what they have accomplished since World War II; they ought to give it greater publicity.

H. E. THELANDER, M.D.

1963

I. A COLONY OF RETARDED CHILDREN SEGREGATED ACCORDING TO FUNCTION will show up how?

1. How many are ambulatory and have accomplished the following:
 - Dress and Undress
 - Feed self
 - Some speech
 - Toilet trained
 How many have prospect of accomplishing the above but are either too young or have not had the opportunity to learn?
2. How many have fairly good intelligence but are too physically handicapped to be self-sufficient?
 - Can any in this group be used in a supervisory capacity for those ambulatory but more retarded?
3. How many are there with a loss of one or more of the special senses?
 - Deaf
 - Blind
 - Aphasic
4. How many are there with multiple severe handicaps?
5. How many have major medical problems?
 - Hydrocephalus
 - Open Spina Bifida
 - Urinary Fistula etc.
6. How frequent is the request for emergency admissions?

II. COMMUNITY CARE OF THE RETARDED.

If local communities are to assume greater care for the retarded, which of the above categories can be satisfactorily managed at a local level and which ones will need a State Institution?

1. The basic needs of the handicapped are the same as those of the normal.
 - Home
 - Medical Care
 - Training and possibly some Education
 - Recreation
 - Religion
 - Many will also need equipment (wheel chairs, crutches, etc.)
 - Transportation
2. Homes.
 - Own home. Foster home. Church home. Boarding School.
 - Adolescent retarded children often need a Boarding Home or School as they become too difficult to be handled by the mother.

Should the State Schools for the blind and deaf take the retarded blind and deaf children? Have the local communities provided sufficient facilities for the normal blind and deaf children, making the above change possible?

3. Medical Care. In addition to routine medical care, there should be a facility for total evaluation of the child's potential. Such a facility should be in a pediatric department and can be set up very much as the clinical laboratories are with a Pediatrician in charge of a non-medical staff. This takes it out of the category of a Center for the Retarded. Parents need a place to go to before they accept the child as retarded.
4. Training. For the very young child the community should provide the following types of nursery schools:
 - For the deprived
 - For the Physically handicapped
 - For the emotionally disturbed (Autistic)
 - For the retarded
 - For the deaf
 - For the blind
 - For the aphasic
 For the school age period:
 - Point I classes
 - Point II classes
 It is very difficult to fit the retarded child with a second handicap into any of the special classes such as: Classes for the blind, deaf, speech, or hyperkinetic.
 - For the young adult
 - Work shops
5. Recreation. This should be provided by public funds but until it is the voluntary health agencies should contribute toward it.
6. Religion. The churches have begun to assume greater responsibility for the retarded. There are many things the churches can do beside giving religious education.
 - Homes are needed
 - Counseling of parents
 - Counseling of individuals who are slightly retarded
7. Transportation. This should be community wide for all handicapped children.
8. There should be a central service for equipment such as wheel chairs, crutches, etc.
9. An emergency admission place is most urgently needed. Such a place should be in connection with an existing Institution since the use of such a place is unpredictable. When it is needed it is needed very badly. It would seem that "a minimal Care Unit" in a local Hospital would be the ideal solution. Provision for pay would have to be made.
10. It might be feasible for a State Institution to contract with local Hospitals to care for major medical procedures instead of attempting to provide for all types of surgery in a relatively small population.

H.E. Thelander

Please return to
Thanks
LM

Comments on the Report by Hamilton Associates

I have read with great interest the report made by Hamilton Associates. It represents an extraordinary analysis and will certainly be of great help in future planning at Children's Hospital. I was particularly delighted with the emphasis that was placed on excellence of patient care. Children's Hospital has enjoyed the reputation for excellence and it would be a tragedy indeed if there were a shift away from this emphasis.

There are a few points that I think need very careful consideration by the Board, the Administration and the Staff before making a change or following the suggestions. The first of these that I wish to mention is the Communicable Disease Division. This has been a unique department of the hospital for a great many years; it has contributed a great deal to the reputation of the hospital and by its past two rather famous chiefs, Dr. E. C. Fleischner and Dr. E. B. Shaw. I think we have every reason to expect it to continue to contribute to the reputation of the hospital. To be sure contagious disease have altered a great deal during the past many years, but they have not been eradicated nor is there any prospect that they will be entirely eradicated. Children's Hospital undoubtedly has enjoyed freedom from the staphylococcal problem largely because we have had an isolation unit where the nasty infections could be isolated and an isolation unit where people have been trained to handle these infections properly. One is probably as important as the other.

The statement that other hospitals have no need for such a unit is of course in part due to the fact that they can send the severe troublesome infectious problems to Children's Hospital and continue to take care of them. Furthermore the Veterans' Hospitals that I visit routinely have areas set aside to handle staphylococcus and other severe infections. We do not even know that we may not again have an epidemic of some kind of infectious disease.

Certainly it is important that serious consideration be given to the full utilization of the unit. However, the fifty percent occupancy quoted is unrealistic. It is practically impossible to have twenty beds in that area. It is uneconomical undoubtedly to handle less patients than that by one set of nurses. The floor however could be expanded in the future and the record room area relocated. The number of beds could then be extended. It would be my suggestion that this floor be maintained as a contagious disease unit but that its services be extended to assist with other types of problem cases. I am thinking particularly of the retarded hyperkinetic child whom I have to hospitalize fairly frequently, and it might be wise to hospitalize some retarded patients and some psychotic patients in this area. They both are disturbing to other patients and such isolation would be worth considering. This might include hospitalization for some alcoholics.

The second point I wish to take exception to is the statement about pediatric surgery. The impetus among pediatricians and other physicians who are interested in the child is definitely to utilize pediatrically trained surgeons for childhood opera-

tions. I do not think this trend can be stopped. There are many forces trying to stem it but if we are going to look to progress in the future our children are going to have to be taken care of by people specially qualified surgically to take care of them. Pediatrically trained surgeons should also set the policies for such a floor.

The location of a new addition is for others to decide but serious thought should certainly be given to the recommendations of the Associates not to clutter up the big space on Maple Street with small disconnected buildings but leave it clear for major future buildings. There may also be something to be said for having the Out-Patient Departments in close proximity.

Signed,

H. E. Thelander, M.D.

March 27, 1963

HET:lw

March 27, 1963

Edward B. Shaw, M.D.
Chairman, KO Polio Program
250 Masonic Avenue
San Francisco, California

My dear Dr. Shaw:

I see by the paper today that the KO Polio funds have not been entirely utilized and the intention is to give the funds back to the communities in which they were collected to be used for children. I would like to make a strong plea that some of this money as indicated below be given to the Child Development Center at Children's Hospital in San Francisco. In this Center we are making a big effort to study children who suffer from any type of neurological insult. The study is long-term follow-up and counseling of the parents regarding the adjustment of the child to his work at school and so forth. It has been an exceedingly rewarding work. Parents have been very grateful for the help. We have funds now from three sources, namely the United Cerebral Palsy Association, the March of Dimes for Congenital Defects, and CCS supports a neurological diagnostic center there. The funds obtained from these do not cover the work we are doing and we would run short about \$10,000 to \$15,000 if we expanded to accommodate the patients referred to us for such careful assessment of their whole potential. The following staff is used for the study, namely: psychologist, educator, speech and hearing consultant, reading consultant, and social service worker. About the only laboratory work we do which adds to the cost on this type of child is the EEG. In the Child Development Center we are following children who have had encephalitis, meningitis and poliomyelitis. If there is any question of any pathology following vaccine, we would be particularly anxious to study them. We are also following children who have had skull fractures and some children who have early had severe dehydration and another group of children who may have suffered hypoxia for any other reason due to anesthesia, drowning and so forth.

It has been well-documented by studies across the United States that the nervous system can take very little insult without leaving some scarring. Furthermore the children who have suffered such scars are often not recognized until they enter school. They are then considered either as an emotional problem or mental retardation because they have difficulties in certain areas of learning. Furthermore it is from this group that many of our other problems arise such as school drop-outs, truancy, delinquency, emotional withdrawal and psychoneuroses.

I hope the Committee will recognize the close connection of this type of work with the aims and purposes of the drive to eliminate polio as one of the big neurological diseases to be conquered.

Sincerely,

H. E. Thelander, M.D.

HET:lw

July 11, 1963

Robert B. Kugel, M.D.
Child Development Clinic
Dept. of Pediatrics
University of Iowa
Iowa City, Iowa

Dear Bob,

I will accept the chairmanship of one discussion group. I would like to use a few slides to introduce the subject; like one on statistics in San Francisco showing the numbers and varieties of severe handicaps and one on the unmet needs in the city. I thought this would be a good take-off point for discussion of planning at local levels. I am mentioning this as I will need a projector. If not available I could put the figures on a blackboard in advance.

I hope the meeting will get down to ground floor planning! As I have said innumerable times, the money is all expended before it gets down to direct service to patients and their families. It is like Hawaii rain that evaporates before it reaches the ground, the ground remaining arid. If we are going to provide adequate care and help, we have to do more than have centers in Medical Schools, much as these are needed. Ninety Medical Schools cannot possibly reach all areas in the U.S. for total care of the children who are retarded and handicapped. There will be a great many people grabbing for the money without having much of an idea how to utilize it. This is the reason practising pediatricians should step in and plan.

Briefly I believe:

1. There should be no indigent children. The public agencies should contract with the private pediatric services for care (and/or the Universities where these exist).
2. There should be more hospitals exclusively for adults, thus mobilizing the children in a few places where adequate service and teaching programs can be set up.

3. A pediatric department should not be accredited unless it has a facility for total assessment of the child, psychological, sociological and educational. This should be set up on a basis similar to that of the clinical laboratories with a medical chief and para-medical staff. It should be open to all doctors for referral of patients in need of this service.
4. The pediatrician must help reorganize the other health services and agencies in the community concerned with these children in order to meet their needs.
5. There must be a better balance between research in the laboratories and study of the total child and his functioning in the community.
6. There must be a better balance between teaching per se and service. Our medical schools should learn to cut the umbilical cord when the M.D. is obtained and begin graduate education which then should be continuous through out the lifetime of the doctor and given by a faculty not oriented to undergraduates.

I am enclosing a carbon if you wish to send it to Dr. Davens.

Sincerely,

H. E. Thelander, M.D.

T/q
Encl.

REPORT ON WORK DONE FOR CEREBRAL PALSY PATIENTS

August 1, 1962 to July 31, 1963

	<u>Number Children</u>	<u>Number sessions</u>
Morning Nursery School	36	645
Wednesday Afternoon Group	9	39
Thursday Afternoon Group	8	36
Friday Group Evaluations	7	7
Educational Evaluations	19	26
Psychological Evaluations on C.P. Children by Mrs. Gladys Kassebaum	26	
Psychological Evaluations on C.P. Children by Mr. E. Walton Kirk	4 (Besides C.C.S. cases)	
Speech and Hearing Evaluations on C.P. Children by Mrs. Wilda M. Flower		
Individual	13	
C.P. Children for Joint Evaluation	2	
Group Therapy Sessions	9	195
Physical Therapy		
Nursery School C.P. Patients	33	756
Out Patients, C.P.	55	439
Occupational Therapy		
Nursery School C.P. Children	30	645
Out Patient C.P. Children	25	322
Medical Clinics		
Number of New C.P. Patients Seen	24	
Total Number of C.P. Patients	179	
Total Clinic Visits (Old and new and repeats)	212	

H. E. Thelander, M.D.

PARENT STAFF CONFERENCES

The staff of the Child Development Center has long been aware that the problem of adequate and continuing communication between parents and the staff as a unit is a difficult one to meet. In the past written progress reports were sent to the parents during the school year. In addition parents are seen on an individual basis by the social work consultant; for individual therapies by the therapists; for individual psychological testing by the psychologists and for hearing and speech evaluations by that consultant. They are seen also individually by the nursery school director whenever questions of the child's progress in the nursery school is of concern to them. But it has been difficult for each parent to talk with the whole staff in order for us to help the parent be more fully aware of the diagnosis, treatment and progress of the child within the nursery school group.

This year, for the first three weeks in July 1963, carefully planned parent conferences were held by appointment with the parents and the ancillary staff. Letters were sent to the parents stating a specific appointment time and both parents were invited to attend, without the child. Three conferences per day were held until we had met with most of the 32 parents. In most instances both parents came. The conferences were held on an informal basis but in general they followed the pattern of our regular staff conferences. The child's referral source, previous medical care and the child's status at the time of referral was reviewed; each staff member reported in his own field on the child's progress. Plans for the coming fall term were outlined. Many of the children are returning in the fall to the nursery school groups; several, however, will be transferred to facilities for which they are now ready. One child, now over age for the group and for whom no facility is available was terminated for nursery school attendance. The parents of this child recognized clearly that the staff had worked very hard with their child; the parents are realistic about the child's degree of mental and physical handicap, but they are not ready to consider placement in a State Hospital. Additional plans were made for the child to attend the program for the handicapped at Fleishhacker, for home bound physical therapy and for continuing in our medical clinic.

Prior to each conference with the parent, the staff met to plan the discussion. Under the guidance of the social work consultant our reports were geared to the parent's readiness to assimilate the larger goal of overall family adjustment to living with a handicapped child, and the somewhat more immediate goals of measuring progress on a day to day basis. Parents needed to verbalize their concerns over such questions as "Will she be able to marry?", "Will he be able to take a job?", to "Will she be able to go to a normal kindergarten?". The staff needed to re-enforce the concept over and over that the evaluation of many of the children is a process which takes a long time. Our inability to predict many aspects of the child's future was often disappointing to the parent, but often also reassuring.

The conferences were successful. One mother indicated that if her parents could share information with the staff her task as the single parent of a handicapped child might be somewhat easier since the grandparents had the care of the child while the mother worked, and their concept of the problem was somewhat limited. In two instances where the father was unable to come at the time we had selected, the mother requested another conference and such was arranged. Most appointments were made after discussion with the family as to the time most suitable for both parents. In many instances attendance at this conference marked the first participation of the father in the program, participation often long sought by the mother who may have been bearing the burden of the child's care alone. In each instance, the staff felt, the father left with a clearer picture of the staff goals for the child; more aware that the medical staff was also often unable to offer a definite prognosis for the young pre-school child. Again, it was helpful to the father to hear that the evaluation of these young children is a process. Often the father verbalized a

deep concern for his wife's continuing fatigue, depression or tenseness, even aware that she was becoming somewhat immobilized by the strain of attempting to cope each day with the endless problems of a severely retarded, physically handicapped child.

We hope that in the future more conferences like these can be held with the parents at the end of the school term, and at any other time if indicated.

Obviously this is only a supplement to the work of our parent educational program in the Parents' Club which meets monthly, the work on an individual basis with the social work consultant, and the medical clinic visits, and it does not eliminate the day to day informal contact with the parents as they bring their children to the nursery school. This "summing up", however, brought the parents and the whole staff into a much closer working relationship; the parents were able to experience a diagnosis and its implications. Both parents left with a clearer picture of the staff's work individually and as a team. Both parents, as a result it is hoped, will have a deeper understanding and awareness of what attendance in a diagnostic and therapeutic center does for the child.

(Mrs.) Jane Sledge, Director
Nursery School Program

July 31, 1963

SOCIAL WORK CONSULTATION IN THE CHILD DEVELOPMENT CENTER
January 1 to June 31, 1963

Total number of families receiving service	182
Number of cases: One interview	68
Number of cases: Two or more interviews	57
	<u>125</u>
(Many nursery school families have had 10 or more interviews)	
Telephone contacts with families (not seen during this period)	20
Number of families involving contact with other agencies	90
Two parent groups met one time a week and averaged 4-6 parents	

Shortcuts have been used to extend social services as far as possible. For example, the use of a group approach with parents with similar problems. This is useful not only for economy of time, but what parents have to offer each other. However, it is only a partial solution. We have found that families with a handicapped child have not been spared other problems as well. Therefore, this frequently means additional individual counselling with families around the needs of other members and referral for appropriate helps.

Dictation has been cut to a minimum but again in a program of multiple disciplines dictation is necessary for communication among the staff. In addition to seeing patients and working with other agencies, the social worker is expected to attend the regular Friday staff meeting; the nursery school coordinating conference, the Tuesday clinic and be available for Thursday clinic.

Interviewing with parents includes initial orientation interviews with parents; participation in ancillary staff evaluations of a child; Crippled Children Services evaluations; regular contact with nursery school parents and follow-up contacts with families where children have moved on to other programs. For example, we have continued to follow families from the beginning of the program 10 years ago; what is the patient doing now, what problems does his care involve for the family, what resources could be useful. However, it is this group that pose problems in setting limits in social service. Unlike the rest of the staff, the case continues after the child has left the nursery school program.

Because of the pressure of work, community participation has been limited to: The Inter-Coordinating Council for Mental Retardation (Dr. Kimmichs committee), Family and Children's Council, CONCERN (a statewide committee to review legislature proposals for health, educational services for special children).

In December, I attended the annual conference on birth defects sponsored by the National Foundation. Since January, I attended the University of California Conference on: The Broad Spectrum of Brain Damage, the Child Welfare League of America, Western Regional Conference and supervised a social work student from San Francisco State College.

Social Service Needs:

It is not possible to see new families coming into the program as quickly as it is often desirable. The parents in the Nursery School program represent an average caseload in

most social agencies. It is not possible to counsel parents without some community participation to be informed on increased services and resources. Follow-up is often inadequate. It is the aggressive client who keeps the contact with the Center on a regular basis who gets the most service. Very often some of our older families do not return until a severe crisis has developed. These situations could often be handled more effectively if followed up earlier.

The experience of the past several years has sharpened our awareness of the needs of the child with a handicap and his family, and brought about a recognition that these will be long time needs. As the child changes, as the family circumstances change, new social and personal problems present themselves. In addition, counselling with families is also closely related to changing attitudes in the community and the development of additional facilities.

(Mrs.) Gertrude Saxton
Social Work Consultant

July 31, 1963

MEDICAL REPORT

The past year in many respects has been both a satisfactory and a hopeful one.

The "alumni" continue to be followed once or twice a year or sometimes once in two years if all is well. It is a great satisfaction to have parents return in between times for advice when problems regarding their children arise. An "open door" policy for these parents is now well established. The social worker for the Child Development Center, Gertrude Saxton, gives fully half her time to Cerebral Palsy patients. Wilda Flower, speech therapist, and Gladys Kassebaum, psychologist, similarly are ever ready to help when their skills can be of service.

Many of our children are now at Sunshine School where they are followed medically by Dr. Else Cabos who is the liaison between the Nursery School, Medical Clinic and Sunshine School.

Several children are in regular school classes and doing well. An increasing number of referrals to the Center are coming from Well Baby Clinics and School Health physicians; the latter referrals are usually children with minimal brain damage and learning problems.

As the children get older more of them are in need of surgery and the hospital wards almost always have two or more patients from the Center. The "Hospital Adjustment" program and the visits from the Center staff make these hospital stays less traumatic for the children.

Several of our children are now teen-agers and Childrens Hospital Youth Clinic has accepted some for guidance through that stormy period, made no easier by a handicap. This clinic sometimes eliminates the necessity of referral to a Psychiatric Center.

There is a growing list of children with no available facility for training. These are children who have had a diagnostic study and a total assessment of their abilities as well as a social diagnosis. Every effort has been made to prepare the children for one of the City's school situations but they have been rejected. There is an urgent need for a Day Care facility. This need has been emphasized before. This city should not continue much longer without providing some such facility for the families whose children are barred from all the educational classes. Sonoma State Institution has been very co-operative in helping us with acute and pressing problems, and Napa State Hospital has come to the rescue for an occasional case. Dr. Marcia Levin, a former resident at Childrens Hospital, acts as our liaison physician at Sonoma.

One of the greatest assets to our handicapped children is the facility at the Fleishacher Pool, "Recreation for the Handicapped". This service is often the only one open to those so severely handicapped that all other doors are closed to them. This unique program deserves the community's whole-hearted support. It is indeed a curious fact that so little thought has been given to the year-round recreation needs of the children who cannot take part in the regular recreation activities.

The religious needs of the handicapped, similarly, have been largely ignored. Sister Miriam's classes in religion for handicapped children of all faiths have demonstrated the need for such services. Some of the other religious bodies in the City have shown some interest. One child on admission to Sonoma said to her mother, "At last I can go to church".

Other activities at all levels point to a happier time for children with handicaps. Locally, the work of Dr. Robert Kimmick and the Council formed under his leadership hopefully will mean that San Francisco is moving toward better care for the retarded children, many of whom are also victims of cerebral palsy. At the state level a number of changes have been instituted that should help in planning for the handicapped and retarded; the independent

departments of Public Health, Mental Hygiene, Special Education and Public Welfare are being brought into closer working relationship through a committee representing all of them in order to co-ordinate the various aspects of the problem. A Commission has also been established to deal with programs for the retarded.

At the National level, the President's action, first, to establish an Institute of Human Development, and second, a Commission on Retardation, should facilitate the programming for all children with defects. The selection of Robert Aldrich, M.D., to direct the Institute of Human Development is a happy choice. His parents were the authors of "Babies are Human Beings". Under the Aldrich influence it can be hoped that the retarded and handicapped will also be given the status of "Human Beings".

The Academy of Pediatrics, through its Child Development Section and its Committees on the Handicapped and Retarded, is having a marked impact on Pediatric training and practice.

Help for any handicapped child, whether his problem is physical, mental, emotional or social, (in most cases it is a combination of all), must start with a correct diagnosis. The rapid advances in the basic sciences, especially genetics, chemistry, embryology and neurology, makes it even more important that children with any type of defect remain under medical supervision and observation in order that new symptoms or signs may be observed promptly for further elucidation of the diagnosis and for correction or treatment whenever this becomes available. Furthermore, diagnosis must be followed by a careful assessment of the child's total abilities, physical, mental, emotional and social, in order to place him properly and to counsel both parents and schools regarding such placement. With increased sensitivity on the part of physicians to defects and neurological abnormalities, more infants and very young children are referred, either with a diagnosis or suspect. It has been amply demonstrated that a hospital-based program for the very young is preferable to either a school clinic or a public health clinic. Physicians in practice are the first to be called upon when the parents become concerned. Physicians are accustomed to send a child to a hospital for further diagnosis. A center set up to assist them with the diagnosis and assessment of the child can be considered comparable to the Clinical Laboratories with a pathologist in charge of a paramedical staff. There are other advantages to a hospital setting for the observation and treatment of infants and toddlers. This is the period in which the parents have the greatest number of questions; they need to have access to a facility that includes physicians readily available daily and all day long. This age period is also the time when it is most difficult to know or to predict the child's final status. It is equally important that the ancillary staff has physicians available with whom they can discuss their observations and questions. The physicians also learn a great deal from the objective and experienced observations of a skilled ancillary staff.

A group of children that concern the staff greatly are the ones with learning difficulties on an organic basis. In 1958 members of the Center pointed out this problem in an article entitled "Learning Disabilities Associated with Lesser Brain Damage", published in the Journal of Pediatrics, October, 1958. The reprints of this article were in great demand and were quickly exhausted. Since that time, studies by the California State Department of Public Health have further documented these observations. Legislation has also been passed making provision for this education. Several participants in these studies have expressed their scepticism of the entity prior to their own studies. As noted earlier, these defects often are not detected until the child enters first grade and cannot master the three "R's". They can be detected earlier. Early detection can be facilitated by making physicians alert to early signs; by having an acceptable diagnostic facility to which children suspect can be sent for study, and by having children "exposed to risks" return for follow-up studies. Dr. Leonard has followed the cases of meningitis and encephalitis over a period of several years. Children with skull fractures or severe

concussions are also followed.

These, and other marginal or fringe children form the reservoir from which come many of the neurotics, delinquents and inadequate citizens.

An incident the other day illustrated dramatically the course of events when the patient is diagnosed but not further followed or guided. When evaluating a child from a foster home, it was learned that the real mother had a history of hemiplegia at 5 years of age. The mother was called in and she related that she had not only had a hemiplegia but she had had seizures and a loss of speech. Her subsequent history reveals an unsuccessful marriage and a child of that wedlock removed from her care; three other children born out of wedlock, one of whom died and the two others are in foster homes. This girl is now 29 years of age. Her deliveries occurred in the same hospital in which she had been hospitalized as a child. Maybe we are optimistic in thinking that new methods of management will be more successful than the old, but at least the old have been so unsuccessful that re-development is indicated. Re-development of community services in conformity with newer knowledge is at least as important as is re-development of our blighted areas in dwellings.

The GOAL, naturally, is to help as many as possible of the individuals with defects to become self-sufficient. When this is not possible, the type of medical and ancillary care described make other adjustments and placements acceptable to the parents.

The Center has been used by many schools and colleges for the education of students; among these students have been nurses, educators, public health personnel, medical students, physiotherapists, occupational therapists and social service personnel.

Members of the staff have participated actively at all levels, local, state and national, in helping to bring about some of the changes that are taking place. Talks and consultations have been given to several groups and to Boards in this and in neighboring counties.

The most urgent present need is money for direct services to the children and their families.

It is of no value to the patient if money is spent in training personnel and then the facility giving the services is left without money to hire such persons. Similarly, if money is given for research but the knowledge gained does not reach the patient because service programs lack the funds for proper staffing, the purpose of the research fails in fulfillment. Regardless of the amount of money that is raised (publicly by taxation and privately by the innumerable charity drives), like the desert rain, it evaporates before it reaches the ground. The earth remains parched. The focus must get back to the patient and his and the family's problems if we are going to make any inroad on the many facets of human needs. Individuals who volunteer their services to Boards and Councils have a grave responsibility to see that the funds entrusted to them are not expended on a superstructure that employs more and more personnel that have less and less contact directly with the patients. Donors, in general, believe that the money they give is for service. There is an increasing trend among those sophisticated in the field to write off those private organizations that return little or none of the moneys collected to service programs in the community.

In behalf of all the physicians connected with the program, I wish to express our appreciation for the loyalty and devotion of the rest of the staff, Mrs. Jane Sledge, Educational Director; Elizabeth Diringer, Physical Therapist; Marjorie Lund, Occupational Therapist; Mr. E. Walton Kirk, Psychologist, and those previously mentioned, and our Secretaries, Mrs. Reed and Mrs. James, who perform the impossible task of typing for all of us, answering the phone calls, making appointments and tolerating our constant interruptions.

H. E. Thelander, M.D., Director
Child Development Center

July 25, 1963

cc: The Board of UCPA San Francisco
cc: The Board of Childrens Hospital

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JEROME R. WALDIE

ASSEMBLYMAN, TENTH DISTRICT

CONTRA COSTA COUNTY

MAJORITY FLOOR LEADER

July 13, 1964

H. E. Thelander, M.D.
Children's Hospital
3700 California Street
San Francisco, California

Dear Dr. Thelander:

Thank you for your letter of July 9 with recommendations for improving services for handicapped children.

I was particularly impressed by your information that most hospital pediatric departments average about 50% occupancy and that the State could contract with such hospitals for care of the retarded.

I am enclosing a copy of our committee's preliminary proposal which, if enacted, could allow for such arrangements. Our committee will be very interested in your reactions to the proposal and I am looking forward to hearing from you again.

Sincerely yours,



JEROME R. WALDIE, Chairman
Subcommittee on Mental Health

JRW:am

Enclosure

I have read the report with great interest
1. I feel very few people have had the opportunity that we
the parent 12-47 had to see a cross section of retarded individual
in a community.

The enclosed ~~is~~ sheet is was made
up. to help parents & ~~staff~~ ^{unorganized} individual
in a community to start thinking about the
problem realistically, at home, in the daily
routine of living.

I Shift again when day is made

II Belvalle

III Centers

C p 129

Children

Parents

Community

1. Foster homes

Nursing homes

Psychiatric Clinics.

Money.

Dup

Letter to the Editor,
American Journal Diseases of Children:

The recent wailings of the pediatric Jeremiahs prompt me to offer these suggestions. The feelings of anxiety and fear apparent in the writings arise from loneliness. Pediatrics is so far ahead of the other specialties that a full time pediatric professor is bewildered. He yearns for the sheltered cloister of the wards with the old familiar diseases about him and the exchange of medical lingo with his confreres in the other specialties. Instead of seeking comfort, thus, in regression an aggressive approach should be tried. There are two ways the academic pediatrician might do this. One is to teach pediatrics, not only to medical students but to the rest of the faculty of the school. This might hasten the closure of the gap between his department and the others. The other way is for the academician to widen his own horizon by learning more about the practice of pediatrics from his confreres in the field.

I. The first of these, namely, pediatric education for the medical school faculty, could be developed in a manner something like this:

1. For obstetricians the rounds once a month could be used to parade before them the children with sequelae from excessive sedation, hypoxia, strangulation, trauma, and respiratory distress.

2. For the anesthetists and surgeons, in addition to the sequelae from hypoxia, those from water intoxication and cardiac arrest should be shown.

Since surgeons like movies, a film might be made comparing the emotional reactions in two situations, as follows: One in which a two-year old returns from eye surgery blindfolded, arms and body restricted (so as not to remove dressings) and the mother's presence prohibited. The other an American traveler, probably in the southern islands, arrested (as possible spy), blindfolded, bound, and prohibited a visit from anyone who speaks his language.

3. For the radiologists (who give lip service to limitation of radiation exposure) compulsory attendance at pediatric tumor conferences and compulsory recording on every pediatric chart the number of films taken.

4. The pharmacologist must be taught that babies do not spring from the womb as little adults who only need to be inflated to reach full size. Drug dosage cannot be merely proportionately reduced. Remember oxygen! chloromycetin! dihydrostreptomycin!

II. In order to widen his horizon, it is suggested that the academician set up exchange programs with practicing physicians for three or six months or longer. These could be done in lieu of Fullbright's or Sabbaticals in Paris. Such an arrangement would give the professor an opportunity to learn practice firsthand. It would give him a slightly different concept of the work day, the function of the telephone, and also he might discover not only the gratification of saving a life from time to time but the joy of starting young parents on the right path in child rearing.

As a special contribution he could help the clinician set up "The Controlled Experiment" that would give an answer to such questions as: How many points was the I. Q. lowered in Baby X when he suffered 7 minutes of apnea during a herniorrhaphy?

The clinician in the role of the professor could use his extra time to become better acquainted with his family, to attend the theater or opera on occasion, and he might get a free trip to a medical meeting. He might even find that with a full time salary and some consultations he made more money than he did in the field.

The basic science personnel undoubtedly would welcome some refreshing clinical observations and might even get some new ideas to pursue.

Since the professors now dominate the editorial boards, the program committees of the pediatric societies, and the advisory boards of Funds and Foundations, the clinical observations and ideas die aborning. The clinicians were grateful for the still small voice of Dr. Robert Cooke in the recent symposium and for Sir Howard Florey's comments on observation and intelligence versus laboratory experiments.

In the future all medical education (not only pediatric) will be based on the study of MAN, his growth and maturation, his structure, function, chemistry, physiology, behavior, and reproduction. Disease will no longer be a "Conversation Piece" on the ward or in the laboratory. It will be taught as a deviation from the normal due to trauma, invasion, degeneration, or internal or external stress. The physician's function will be to prevent disease, detect it early, and eliminate it promptly.

H. E. Thelander, M.D.

DANIEL BLAIN, M.D.
DIRECTOR OF MENTAL HYGIENE

EDMUND G. BROWN
GOVERNOR

D. M. BRAMWELL, M.D.
SUPERINTENDENT AND
MEDICAL DIRECTOR



STATE OF CALIFORNIA
DEPARTMENT OF MENTAL HYGIENE

Sonoma State Hospital

ELDRIDGE, CALIFORNIA

May 23, 1963

Hulda E. Thelander, M. D.
3641 California Street
San Francisco, Calif.

Dear Dr. Thelander:

Thank you for accepting the speaking engagement on October 15, from 8:00 to 10:00 p.m., at Sonoma State Hospital, which is part of a series of six weekly presentations under the title of "Mental Retardation in Medical Practice". As you recall, this program is jointly sponsored by Sonoma State Hospital and U. C. Continuing Education in Medicine and Health Sciences with the aid of a National Institute of Mental Health grant.

The title I have given to your presentation is "The Physical Evaluation of the Infant and Child Who May Be Retarded". I would suggest that you include comments on the evaluation of the physical and emotional aspects of the infant and child's behavior, particularly between the ages of birth to six or seven years. Realizing that you will be addressing hopefully a group composed of generalists, pediatricians and obstetricians, I am certain that you will be well oriented as to what is most important to stress.

You will receive an honorarium of \$75.00.

Thank you for your assistance.

Very truly,

A handwritten signature in cursive script that reads "James C. Dawson, M.D.".

James C. Dawson, M. D.
Acting Chief of Professional Education

JCD:ab

cc: Dr. Bramwell
Dr. Finner

SEP 14 1963

Strangulation by the Umbilical Cord

EDITORIAL OFFICE

An article in Acta Paediatrica by J. Selwyn Crawford, M.D.C. entitled "Cord Around the Neck Incidence and Sequelae" prompted me to resurrect an article of mine on the same subject rejected some three years ago. With the increased interest in the causes of mental retardation and brain injury to the young, I wish to try again to call attention to cord strangulation.

Near strangulation by the umbilical cord poses an intriguing problem in body dynamics. It is the only situation in which the essential life line of the individual is responsible for strangulation. Among the factors that influence the outcome are 1) the unique quality of the umbilical cord to resist obstruction; 2) the ability of the heart to keep up the necessary pressure in order to maintain circulation; 3) the effect of the strangulation on the local tissues; and 4) the effect of the strangulation on the circulation to the central nervous system. Other factors that need to be considered are the size and sturdiness of the infant, the duration of the strangulation, and the recognition and prompt resolution of the dilemma by the attending physician. The latter may avoid secondary pathology such as premature separation of the placenta or delayed delivery due to the shortened cord, and the consequences of the events on the infant.

I noted as did Crawford that literature on strangulation is meager. (1) Crawford states that in 1/3 of 628 consecutive deliveries the cord was around the neck. Banner et al (2) in a study of 14,886 live births and 190 intra-uterine deaths attributed derangement of the umbilical cord as the cause of death in 25 instances. In 15 of these death was due to prolapse of the cord and in only 10 was the cord twisted around body and neck. Shui et al (3) in a study of 1,000 consecutive cases producing 1,007 children reported that looping occurred in about 20%. Earn (4) in 1959 reported on looping of the cord in 5,676 consecutive deliveries. There was only one death in this group and that was in a child with eight loops about the neck. He found looping in 23% of all cases. Between July 1955 and January 1957 Dr. Frank Stangl (5) while resident at Children's Hospital made note on cord curling. He found curling in 15.7%. In this series note was made as to whether or not the child was in distress at the time. In the analysis of 415 of the 420 cases 331 showed no respiratory or circulatory difficulties nor any other abnormalities at the time of birth or during the neonatal course. In 84 cases there were signs of distress ranging from "slow to cry" to more severe problems either during birth or in the neonatal course or both. As a follow-up of this study during the two years that the hospital participated in the Collaborative Study (6) recording on the condition of the cord was made on 550 deliveries. Those with looping about the neck are recorded as loose in 59 instances and tight in 32. The percentage of the total cases that showed some looping was 17.7.

Keckt (7) reviewed 3 cases of attempted suicide by strangulation in adults. Two of these showed temporary palsy of both cranio-pharyngeal nerves. One showed a retrograde amnesia. These two cases were normal after two months. The third case reported by Keckt had unilateral laryngeal palsy. There was at first anesthesia and then hyperesthesia of the larynx. This patient also improved after two months. Russian authors (8) experimenting on cats summarized their findings in the statement: "The immediate cause of death in strangulation is paralysis of the vital centers in the medulla oblongata due to anoxia of asphyxiation and increased intracranial pressure".

In the Child Development Center there were 8 out of 450 consecutive cases in which cord strangulation was implicated in the history. In some instances the cord was not only around the neck but around a limb also or knotted; in others delayed

delivery or premature separation of the placenta had occurred, presumably secondary to the shortened curled cord. These children, except the one reported herein, are moderately to severely retarded. The one case of apparently pure strangulation has been followed since birth. In view of Keck's (7) reports of local injury to the innervation of the larynx in attempted strangulation in adults, this case is provocative.

D.R. is a female child born 6-25-57 of normal healthy parents. She is a second child. The older sibling is living and well. The pregnancy had been normal. The infant was delivered 15 days prior to the estimated date, weighing 4 pounds, 15 ounces. The cord was wrapped very tightly about the neck four times. No other pathology was observed. Her face was highly suffused and there were scattered petechiae over the face, neck and scalp. In addition to these findings the nurses reported and described the baby in the newborn nursery as having a curious "no voice" cry.

At 11 weeks her weight was 9 pounds 2 ounces. Except for her small size and a curious feeble, hoarse sounding cry there were no abnormalities found. At 9-1/2 months her weight was 17 pounds 7 ounces. She was an extremely quiet child but was responsive and smiling. Again this very curious quality of her voice was noted. She walked at 14 months. Her father described her as having two voices, a very feeble, hoarse voice, and at times a high, squeaky one. At 2 years she was referred to Dr. R. C. Martin for a laryngeal examination. He found that there was some webbing of the cords. This was corrected without, however, altering her voice to date. This child has had three developmental tests. In the first of these she fell within the low normal range. In her second at 19 months she was given a score barely within the normal range. The last test done at the age of 29 months revealed that her communication was mostly by gestures. Her performance was erratic and scattered and she had only one success at her own age.

Discussion

In the case of strangulation by the cord a local effect on the neck vessels and nerves should be considered as well as the interruption of the blood flow within the cord and of the total blood flow to the central nervous system. The Wharton's jelly of the cord acts as a buffer against any vessel injury or block, thus tending to keep the circulation of the cord intact even with considerable tension and pressure on the cord. The fetal heart responds with extra work to maintain the circulation but in the normal fetus it appears able to do so. When the cord is cut under circumstances of strangulation, the intense pressure of the blood has been noted. The frequency with which these children survive without sequelae probably indicates the relatively short time that strangulation is in effect. Crawford also noted this. Actual strangulation when it does occur probably is at its maximum during the expulsion of the infant. This idea is confirmed by Dr. Stangl's studies in which he noted that in the group of children showing no distress at birth, only 13.5% were recorded as having the cord under tension, whereas in the group that did show distress, 25% of the cords were described as under tension. Criteria for distress in the two groups of cases were as follows: In the A group where there was no tension on the cord 1.2% showed evidence of distress whereas in the group with tension on the cord 10.7% showed distress. Another factor of interest and worthy of note in the series was the low incidence of curling in prematures. There was a higher incidence of signs of distress in both groups when deliveries were spontaneous, in other words, when the second stage of labor was prolonged. Conversely there were fewer babies in the distress group when forceps were used. This emphasizes the necessity for careful observation of the fetal heart during the second stage.

There has been too great a tendency to assume that the infant who leaves the newborn nursery without gross neurological findings has escaped brain injury. There is increasing evidence that minimal insults may become apparent only at the age when the child is assuming more complicated functions in the field of learning, comprehension and judgment. The intense suffusion of the face and the petechias that are seen with strangulation suggest the likelihood of petechial hemorrhage in the central nervous system and at times of temporary hypoxia. In order to ascertain whether or not surviving children may show late sequelae, children with cord strangulation and distress should be followed for several years to determine whether or not difficulties will arise in more subtle areas as these children grow older, namely, in speech comprehension, reading ability, memory and attention span. The possibility of local injury to the structure of the neck should also be considered.

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H. E. Thelander, M. D.
Director Child Development Center
Children's Hospital, San Francisco

CLINICAL CONSIDERATIONS IN MENTAL RETARDATION
October 1 - November 5, 1963 (PMI 63-15)

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CLINICAL CONSIDERATIONS IN MENTAL RETARDATION



Age 13 Denny

CLINICAL CONSIDERATIONS IN MENTAL RETARDATION

SONOMA STATE HOSPITAL • OCTOBER 1 - NOVEMBER 5, 1963

Mental retardation is one of the most important health problems in the United States today. In fact, the presence of a retarded child in the family influences the life of the entire household. Necessary as it may be in selected instances, custodial care has often proved to be at best an inadequate solution to a very complex situation. As a result a more positive attitude has evolved, leading to a better understanding and acceptance of the mentally handicapped child for whom a reasonably happy life is now possible.

This series of presentations has been designed to provide clinicians with up-to-date and practical information which will be useful in meeting the challenge of mental retardation.

This program is presented by the staff of Sonoma State Hospital, Eldridge, and Continuing Education in Medicine and the Health Sciences, University of California San Francisco Medical Center. It is made possible by a grant from the National Institute of Mental Health.

REGISTRATION

Time: 7:30 - 8:00 p.m.
Date: October 1, 1963
Place: Professional Education Center
Sonoma State Hospital
Eldridge, California
Fee: \$10
(This course carries 12 hours
A.A.G.P. Credit)

LECTURES

Tuesday evenings — 8:00 - 10:00 p.m.

GENERAL PROGRAM CHAIRMAN

JAMES C. DAWSON, M.D., Acting Chief
of Professional Education, Sonoma State
Hospital, Eldridge, California

OCTOBER 1, 1963

A PHYSICIAN'S OVERVIEW
Peter Cohen, M.D.

OCTOBER 8, 1963

SOCIO-CULTURAL ASPECTS
Helen Herrick, B.A., M.S., A.C.S.W.

OCTOBER 15, 1963

THE PHYSICAL EVALUATION OF THE
INFANT AND CHILD
Hulda E. Thelander, M.D.

OCTOBER 22, 1963

CLINICAL GENETIC ASPECTS
Norman Kretchmer, M.D., Ph.D.

OCTOBER 29, 1963

COMMUNITY RESOURCES FOR DIAG-
NOSIS AND TREATMENT
Edgar W. Pye, A.B., M.S.W.

NOVEMBER 5, 1963

SOME TREATMENT CONSIDERATIONS
FOR THE PATIENT AND FAMILY
Irving Philips, M.D.

FACULTY

PETER COHEN, M.D., Associate Professor of Pediatrics, University of California School of Medicine, San Francisco
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HULDA E. THELANDER, M.D., Associate Clinical Professor of Pediatrics, University of California School of Medicine, San Francisco, and Director, Child Development Center, Children's Hospital, San Francisco

Pediatrics

THE JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS, INC.

CLEMENT A. SMITH, *Editor*, 221 Longwood Avenue, Boston 15, Massachusetts

October 4, 1963

Re Ms. #301-63

Dr. H. E. Thelander
Director Child Development Center
Children's Hospital
San Francisco, California

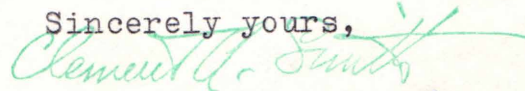
Dear Dr. Thelander:

Brief papers for Experience and Reason are reviewed as promptly as possible. In the case of yours*, I agree with one reviewer who felt it to be unsuitable for that section because of its organization as half letter, half article and, because it contains very little experience for the amount of reason included. I would like to see it begin (without self deprecation as a resurrected rejected paper) as a brief article rather than as a Letter to the Editor re Crawford. (A reviewer has suggested that this is what it should be, in its present form.) I would like it to report the case and then apply whatever information is available on whether strangulation alone, as compared to interruption of umbilical blood flow, can be certified as a cause of death or permanent damage.

This could give it all a much sharper focus and, perhaps, more readers.

We want Experience and Reason to be a strong department. I hope you may be willing to assist us in that way by a revision of this material.

Sincerely yours,



Clement A. Smith, M.D.
Editor

CAS:cb
Enc. Mss. 1st & 2nd Copies

*Strangulation by the Umbilical Cord

Dictated by Dr. Smith, signed in his absence.

American Medical Association

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ADDRESS REPLY TO:

Warren E. Wheeler, M.D.,
Children's Hospital,
561 South 17th Street,
Columbus 5, Ohio

A.M.A. JOURNAL OF DISEASES OF CHILDREN

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November 1, 1960

H. E. Thelander, M.D.
3641 California Street
San Francisco 18, California

Dear Dr. Thelander:

I regret to have to inform you that your revised manuscript (see enclosed) has been rejected by our editorial reviewers for publication in the A.J.D.C. While all considered the revision to be considerably improved over the original paper, they were unanimous in commenting that the supporting material was insufficient to justify publication at the present time.

We sincerely appreciate your taking time to revise the manuscript and hate to have to turn it down for a second time. However, I feel that I would be remiss were I to forsake a policy which currently seems to be successful in improving the quality and quantity of our journal's article. I hope you'll understand our position and I'd invite you to, in spite of these points, contemplate submitting other manuscripts to us in the future. Thank you again.

Sincerely,



Warren E. Wheeler, M.D.
Chief Editor

WEW:R-mb



CHILDREN'S HOSPITAL

OF SAN FRANCISCO

A HOSPITAL FOR MEN, WOMEN AND CHILDREN

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November 25, 1963

Dr. H. E. Thelander
3641 California Street
San Francisco, California

Dear Dr. Thelander:

Your talk before the Board the other day was tremendously interesting. I found myself giving a resume of it at lunch to Peter Haas, who is a great admirer of yours - this served to help fix your points in my mind!

You will let us know, of course, if the members of the Board, individually or collectively, can be useful at any time, to help support community or legislative action in the interest of total service to children.

You were a great addition to our Board meeting - many thanks!

Sincerely,

Mary K. Beales

Mrs. Ross W. Beales
President
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ARTHUR JAMPOLSKY, M. D.
ALAN B. SCOTT, M. D.
2340 CLAY STREET
SAN FRANCISCO 15, CALIFORNIA
JORDAN 7-7272

November 26, 1963

Hulda Thelander, M.D.
3641 California Street
San Francisco, Calif.

Dear Jo,

I just wanted to give you a word of congratulations on your letter to the Editor of the Medical Bulletin. I had to resign from two Boards just because of the things you stated in your letter.

Wouldn't it be possible to have different agencies specify how much percentage of the dollar goes toward direct service to the patient. Then they could not hide overhead that really is overhead, etc.

Keep it up!!! If I can help, let me know.

Cordially,

A handwritten signature in blue ink, appearing to be 'Art' followed by a stylized flourish.

Arthur Jampolsky, M.D.



BAY AREA EDUCATIONAL TELEVISION ASSOCIATION, 525 FOURTH STREET, SAN FRANCISCO 7, SUTTER 1-8861

DECEMBER 4, 1963

DR. H. E. THELANDER
3641 CALIFORNIA STREET
SAN FRANCISCO 18, CALIFORNIA

DEAR DR. THELANDER:

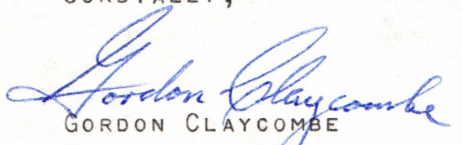
IT WAS INDEED KIND OF YOU TO WRITE YOUR INTELLIGENT AND CONSTRUCTIVE COMMENTS REGARDING DAVID SUSSKIND'S PROGRAM ON "NARCOTICS." I AM SENDING YOUR COMMUNICATION ALONG TO MR. SUSSKIND WITH THE REQUEST THAT HE FORWARD IT TO DR. ROBERT BAIRD.

A GOOD PORTION OF MY ADULT LIFE I HAVE SPENT WORKING WITH THE MEDICAL PROFESSION AT STANFORD, PALO ALTO MEDICAL CLINIC RESEARCH FOUNDATION, AND JUST PRIOR TO COMING WITH KQED AS DIRECTOR OF DEVELOPMENT, FOR THE UNIVERSITY OF SOUTHERN CALIFORNIA SCHOOL OF MEDICINE. IN THE LATTER SCHOOL, BOTH AT THE SELECTION COMMITTEE LEVEL AND IN ORIENTATION CLASSES, I AND MY COLLEAGUES STRESSED THE IMPORTANCE OF DEDICATION. IT IS MY FEELING AND IT HAS BEEN MY EXPERIENCE OVER THE YEARS THAT THE HIGHEST QUALITY MEDICAL CARE IS ONLY RENDERED BY DOCTORS WITH A HIGHLY DEVELOPED SENSE OF DEDICATION TO THEIR PATIENTS AND PROFESSION. THIS CANNOT BE STRESSED TOO HIGHLY.

I WOULD BE REMISS IN WRITING IF I DID NOT INVITE YOU AND YOUR COLLEAGUES TO BECOME SUPPORTING MEMBERS OF KQED, IF YOU ARE NOT ALREADY. IF YOU ARE, PASS THE ENCLOSED RETURN ENVELOPE ON TO A FRIEND OR PATIENT AND HELP US BRING MORE INTERESTING AND THOUGHT-PROVOKING PROGRAMS TO VIEWERS THROUGHOUT THE BAY AREA.

AGAIN, THANKS FOR WRITING AND EVERY GOOD WISH TO YOU.

CORDIALLY,


GORDON CLAYCOMBE
DIRECTOR OF DEVELOPMENT

GC:JG
ENCLOSURE

GEORGE F. SHERMAN, M. D.

3510 SACRAMENTO STREET, SAN FRANCISCO 18

November 30, 1963

Dear Jo:

When you receive this letter, I shall have retired from private practice. I am truly sorry that the state of my health makes this advisable; I have already delayed as long as seems wise. I shall miss very much the pleasant, stimulating company of my patients and their families.

Mrs. Sutton will continue to be available at the office until the middle of January to help you with records and reports.

Thank you for our friendly contacts in the past.

Sincerely yours,



George F. Sherman, M.D.

I'd hoped to see you last week to tell you personally, but everything got all confused. It's not too bad -- more uncomfortable: emphysema, some angina, & my family's progressive Reynaud's. But I expect to be around for a long time!

George

MEDICAL REPORT BIRTH DEFECT CENTER
CHILDRENS HOSPITAL - SAN FRANCISCO, CALIFORNIA

July 1, 1963 through December 31, 1963

New Patients	96
Total Patients Seen	278
Total Visits	318

Visits -	Female 116	Male 202
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Counties:	San Francisco	162
	San Mateo]	58
	Marin	25
	Napa & Vallejo	15
	Santa Clara	13
	Santa Cruz	7
	Sonoma	6
	Sacramento	6
	Yuba	5
	San Joaquin	5
	Contra Costa	4
	Alameda	3
	Butte & Placer (2 each)	4
	Glen, Colusa, Alviso,	
	Humboldt, Reno (1 each)	5

Total 318

Types of Cases - 96 New Patients

1. Neurologically Handicapped with learning problems	26
2. Multiple minor anomalies associated usually with either physical or mental retardation	10
3. Major multiple congenital anomalies - non specific	3
4. Anomalies of Special Senses	
Communication (aphasia)	8
Dyslexia	4
Deafness	4
Visual	4
5. Cranium & Spinal Canal	
Hydrocephally	3
Microcephally	1
Cranium Bifidum	1
Meningocele	2
Encephalocele	2
6. Gonadal Dysgenesis	3
7. Mongols	4
8. Facial Deformities	3
9. Familial retardations	3

10. Miscellaneous

White forelock	1
Osteogenesis imperfecta	1
Broad thumb syndrome	1
Vascular Dystrophy	1
Seizures alone	1
Autism	2

11. Post Central Nervous System Disease 6

12. Post Skull Fracture 1

(These latter two groups are routinely followed.

COMMENTS

In California and especially in the County of San Francisco, the Crippled Children's Services are very generous in the interpretation of cases eligible for diagnostic study. The past year two new laws affecting children with defects have been passed. One states a child is not to be denied the services of Crippled Children because he is mentally retarded. Formerly some counties refused CCS to crippled children who were mentally retarded. The other law provides funds for school departments to set up special classes for the neurologically handicapped child with hyperkinesia and learning problems. The parents' organization for this latter group of children have been very active. This probably accounts for the large number of children seen the past six months in this category. Incidentally, a paper from our Center was published in the Journal of Pediatrics, October 1958 entitled "Learning Disabilities Associated With Lesser Brain Damage". The reprints have been exhausted.

On March 2, 1964, a program for children too severely handicapped to attend any school will be opened at the Fleishhacker Pool Building in connection with Recreation for the Handicapped. It will be a day care facility three days a week. The recreation program for the other handicapped children will continue as before after school hours and on Saturdays. Several of the Churches have also become interested and are providing some type of program for children who are abnormal.

We are anxious to improve the program for out of town children admitted to the Hospital for repair of congenital anomalies. The pediatric department provides an excellent "Hospital Adjustment Program" and in general the children are happy in the Hospital, but the follow through program into the home and community is difficult. It is extremely important. As testimony to this I wish to quote from a letter received the past week from the mother of a boy, now 16 years, born with an extrophy of the bladder: "His physical defect has been surgically repaired, but no one has ever suggested doing anything about the mental anguish he has suffered and apparently cannot cope with at this point. Michael is an intelligent, nice-looking boy who needs some help now. Is there any such help available for him at your Center?"

When talking to a group of teachers last week one gentleman stated during the discussion period, that he had polio at age 3 years and was in braces and on crutches for several years. During that period he was the butt of so much comment and derision that he hated normal children and was always happy when he could return to the Hospital ward. It is help in this area of adjustment for the handicapped child that I hope we can render

service at the community and neighborhood level. The women's organizations and the Churches may be the "portal of entry".

We are finding also that the adolescent with a defect poses a special problem. Both the Youth Clinic and the Child Guidance Service have assisted us with these children.

The non-medical staff have worked out several routines that help expand the services rendered to patients. Mrs. Saxton, our social worker, is especially astute and perceptive in detecting the basic problem in families where adjustments are difficult. Mrs. Kassabum, our psychologist, has had training in Education and is therefore especially valuable with learning and perceptual difficulties. Direct communication with teachers and participation of teachers in conferences on certain children is very helpful. Mrs. Sledge, our nursery school teacher, does very much the same for the pre-school child. Mrs. Flower, our speech audiologist, has excellent rapport with the two speech and hearing centers in the city. The building program calls for hearing equipment at Childrens Hospital, a much needed service.

Although we have refrained from setting up "specialty" clinics within the Birth Defect Center, there is some grouping of cases according to the interests of the physicians. Thus, Dr. Paul Wilson sees most of the adolescents and also the Pulmonary problems. Dr. Elise Cabes spends part of her time in the schools of the city and is therefore a good liaison between the Center and the public schools. Dr. Robert Gray Patton is called upon when growth and endocrine problems arise; Dr. L.M. Leonards has replaced Dr. Shaw as chief of the Contagious Disease Department and follows the children with Central Nervous System disease and injury. Dr. Robert Palmer, neurosurgeon, Dr. Knox Finley, neurologist, Dr. R. Kirklin Ashley, orthopedist, Dr. Margaret Henry, ophthalmologist, Dr. E.C. Brown, plastic surgeon, Dr. Pieter de Vries, pediatric surgeon have all given devoted service to the Center.

Our secretaries, Mrs. Reed and Mrs. James, perform an impossible task of typing, answering the telephone, setting up all the various appointments and tolerating the incessant interruptions of the medical and non-medical staffs.

INVESTIGATION

Although our Center is devoted to patient service, clinical observations and ideas therefrom are crowding us to the point where we are looking for an interested colleague in a research field with whom we might share these ideas and pursue investigation of them.

EDUCATION

There is no real concern in the Center regarding its educational impact in the hospital, in the community and beyond. There is some danger that services may suffer because of the demands on the staff by visitors and calls to speak.

H. E. Thelander, M.D., Director
Child Development Center

4/11/63

REPORT ON THE BIRTH DEFECTS CENTER
CHILDREN'S HOSPITAL, SAN FRANCISCO
FROM JANUARY 1, 1963 to APRIL 15, 1963

The Clinics have continued to be held on Monday, Tuesday and Thursday P.M. with the following pediatricians participating - Thelander, Wilson, Cabot. Thursday afternoon is especially devoted to teaching the house staff. Dr. Douglas Crowther, neurologist, is also in attendance that day. Whenever possible new patients are seen on Mondays and Thursdays. The pediatrician examines the child, arranges for any necessary laboratory procedures and requests medical consultations as indicated. Every child is given at least a minimal additional assessment as follows:

1. Developmental or psychological evaluation.
2. Educational evaluation (18 months on).
3. Social diagnosis of home and environment.
4. Interpretation to the parents of the findings with counseling.
5. Report to referring physician.

Additional assessments are made, when indicated, as follows:

Speech and Hearing
Reading

Therapy Medical or surgical therapy, as indicated, is arranged by the physicians in charge and/or the consultants.

Ancillary for the local children and those within traveling distance, the following therapies are available and administered by the physician in charge:

1. Physiotherapy
2. Occupational therapy
3. Speech - group stimulation for young child 3 to 5 years. Some individual speech therapy for older children.
4. Reading for dyslexic children.
5. Pre-nursery school experience for selected young children in need of therapy in a play situation.
6. Counseling by the social worker and physicians.
7. Re-evaluations.

PATIENT VISITS JANUARY 1, 1963 to APRIL 5, 1963 WERE AS FOLLOWS:

New patients	53
Follow-up and return visits	125
Total new and old patients seen	168 (some came more than once)

New patients grouped by diagnosis were as follows:

Anomalies of the central nervous system or suspect	11
Multiple congenital anomalies	7
Chromosomal aberrations	7
Aphasia and speech disorders	7
Growth abnormalities (midgets and suspects)	6
Hyperkinesia and behavioral abnormalities	6
Dyslexia and major ^{learning} difficulties other than mental retardation	3

Degenerative hereditary diseases
Deafness with other abnormalities
Urethral anomaly

3
2
1

53

There have been two deaths during these months:

1 child with meningococci, repair and shunt
1 with Nieman Picks disease

LOOKING TO THE FUTURE

There has been tremendous demand for the services of the Birth Defect Center from doctors and parents. Parents seek help from one medical center after another not because they are looking for a "magic cure" or because they will not accept the diagnosis such as "shopping" is generally interpreted. It is our experience that most parents have accepted the diagnoses and are seeking on-going help. The questions they ask are "What is his future; will he grow normally; will he be able to go to school; will he be able to do a job; will he be able to marry and have children. How can we help him attain his best potential, what are the chances of another child in the family being affected?"

SOME FUTURE PLANS AND SUGGESTIONS

- I. Since many of our patients come from a distance and will have to get most of their services in the local community, we have arranged with the Continuation Courses at the University of California Medical Center to have an all-day workshop in November on "Local Planning for Handicapped Children". To this Workshop will be invited key people from each County or group of Counties such as a physician preferably, a pediatrician, a visiting nurse, someone from the field of Special Education, a social worker, psychologist and someone from Public Health. We hope this will be a March of Dimes Project.
- II. The hidden, subtler abnormalities of the Central Nervous System give us concern, namely dyslexia, less evident aphasia and dyscalculias. These are usually not detected until the child starts school. They are often the basis for truancy, drop-outs and the source of behavior problems. We would like to see hospitals start "Risk registries". A great deal is known about "Risks" to the fetus and newborn as well as to the young child. Obstetrics, pediatrics, surgery and the infectious disease departments should all maintain a registry of patients exposed to risks. (To list a few, Hydranmos, Hypoxia, Cardiac arrest, Meningitis, skull fracture, etc.) This registry would serve as a reference source in the record room of the hospital. It could and should also be the basis for follow-up studies. Prevention can be started now.
- III. Developmental assessment and counseling is of such value to physicians and parents that it should become a diagnostic and therapeutic part of every accredited Pediatric Department. Children are important people. They are entitled to the best care we can devise to help them reach their best

potential. Tightening up all defenses against injury to the fetus and young should have top priority in our health program.

HC Shulander
4/17/63

MEDICAL REPORT

The past year in many respects has been both a satisfactory and a hopeful one.

The "alumni" continue to be followed once or twice a year or sometimes once in two years if all is well. It is a great satisfaction to have parents return in between times for advice when problems regarding their children arise. An "open door" policy for these parents is now well established. The social worker for the Child Development Center, Gertrude Saxton, gives fully half her time to Cerebral Palsy patients. Wilda Flower, speech therapist, and Gladys Kassebaum, psychologist, similarly are ever ready to help when their skills can be of service.

Many of our children are now at Sunshine School where they are followed medically by Dr. Else Cabos who is the liaison between the Nursery School, Medical Clinic and Sunshine School.

Several children are in regular school classes and doing well. An increasing number of referrals to the Center are coming from Well Baby Clinics and School Health physicians; the latter referrals are usually children with minimal brain damage and learning problems.

As the children get older more of them are in need of surgery and the hospital wards almost always have two or more patients from the Center. The "Hospital Adjustment" program and the visits from the Center staff make these hospital stays less traumatic for the children.

Several of our children are now teen-agers and Childrens Hospital Youth Clinic has accepted some for guidance through that stormy period, made no easier by a handicap. This clinic sometimes eliminates the necessity of referral to a Psychiatric Center.

There is a growing list of children with no available facility for training. These are children who have had a diagnostic study and a total assessment of their abilities as well as a social diagnosis. Every effort has been made to prepare the children for one of the City's school situations but they have been rejected. There is an urgent need for a Day Care facility. This need has been emphasized before. This city should not continue much longer without providing some such facility for the families whose children are barred from all the educational classes. Sonoma State Institution has been very co-operative in helping us with acute and pressing problems, and Napa State Hospital has come to the rescue for an occasional case. Dr. Marcia Levin, a former resident at Childrens Hospital, acts as our liaison physician at Sonoma.

One of the greatest assets to our handicapped children is the facility at the Fleishacher Pool, "Recreation for the Handicapped". This service is often the only one open to those so severely handicapped that all other doors are closed to them. This unique program deserves the community's whole-hearted support. It is indeed a curious fact that so little thought has been given to the year-round recreation needs of the children who cannot take part in the regular recreation activities.

The religious needs of the handicapped, similarly, have been largely ignored. Sister Miriam's classes in religion for handicapped children of all faiths have demonstrated the need for such services. Some of the other religious bodies in the City have shown some interest. One child on admission to Sonoma said to her mother, "At last I can go to church".

Other activities at all levels point to a happier time for children with handicaps. Locally, the work of Dr. Robert Kimmick and the Council formed under his leadership hopefully will mean that San Francisco is moving toward better care for the retarded children, many of whom are also victims of cerebral palsy. At the state level a number of changes have been instituted that should help in planning for the handicapped and retarded; the independent

departments of Public Health, Mental Hygiene, Special Education and Public Welfare are being brought into closer working relationship through a committee representing all of them in order to co-ordinate the various aspects of the problem. A Commission has also been established to deal with programs for the retarded.

At the National level, the President's action, first, to establish an Institute of Human Development, and second, a Commission on Retardation, should facilitate the programming for all children with defects. The selection of Robert Aldrich, M.D., to direct the Institute of Human Development is a happy choice. His parents were the authors of "Babies are Human Beings". Under the Aldrich influence it can be hoped that the retarded and handicapped will also be given the status of "Human Beings".

The Academy of Pediatrics, through its Child Development Section and its Committees on the Handicapped and Retarded, is having a marked impact on Pediatric training and practice.

Help for any handicapped child, whether his problem is physical, mental, emotional or social, (in most cases it is a combination of all), must start with a correct diagnosis. The rapid advances in the basic sciences, especially genetics, chemistry, embryology and neurology, makes it even more important that children with any type of defect remain under medical supervision and observation in order that new symptoms or signs may be observed promptly for further elucidation of the diagnosis and for correction or treatment whenever this becomes available. Furthermore, diagnosis must be followed by a careful assessment of the child's total abilities, physical, mental, emotional and social, in order to place him properly and to counsel both parents and schools regarding such placement. With increased sensitivity on the part of physicians to defects and neurological abnormalities, more infants and very young children are referred, either with a diagnosis or suspect. It has been amply demonstrated that a hospital-based program for the very young is preferable to either a school clinic or a public health clinic. Physicians in practice are the first to be called upon when the parents become concerned. Physicians are accustomed to send a child to a hospital for further diagnosis. A center set up to assist them with the diagnosis and assessment of the child can be considered comparable to the Clinical Laboratories with a pathologist in charge of a paramedical staff. There are other advantages to a hospital setting for the observation and treatment of infants and toddlers. This is the period in which the parents have the greatest number of questions; they need to have access to a facility that includes physicians readily available daily and all day long. This age period is also the time when it is most difficult to know or to predict the child's final status. It is equally important that the ancillary staff has physicians available with whom they can discuss their observations and questions. The physicians also learn a great deal from the objective and experienced observations of a skilled ancillary staff.

A group of children that concern the staff greatly are the ones with learning difficulties on an organic basis. In 1958 members of the Center pointed out this problem in an article entitled "Learning Disabilities Associated with Lesser Brain Damage", published in the Journal of Pediatrics, October, 1958. The reprints of this article were in great demand and were quickly exhausted. Since that time, studies by the California State Department of Public Health have further documented these observations. Legislation has also been passed making provision for this education. Several participants in these studies have expressed their scepticism of the entity prior to their own studies. As noted earlier, these defects often are not detected until the child enters first grade and cannot master the three "R's". They can be detected earlier. Early detection can be facilitated by making physicians alert to early signs; by having an acceptable diagnostic facility to which children suspect can be sent for study, and by having children "exposed to risks" return for follow-up studies. Dr. Leonard has followed the cases of meningitis and encephalitis over a period of several years. Children with skull fractures or severe

concussions are also followed.

These, and other marginal or fringe children form the reservoir from which come many of the neurotics, delinquents and inadequate citizens.

An incident the other day illustrated dramatically the course of events when the patient is diagnosed but not further followed or guided. When evaluating a child from a foster home, it was learned that the real mother had a history of hemiplegia at 5 years of age. The mother was called in and she related that she had not only had a hemiplegia but she had had seizures and a loss of speech. Her subsequent history reveals an unsuccessful marriage and a child of that wedlock removed from her care; three other children born out of wedlock, one of whom died and the two others are in foster homes. This girl is now 29 years of age. Her deliveries occurred in the same hospital in which she had been hospitalized as a child. Maybe we are optimistic in thinking that new methods of management will be more successful than the old, but at least the old have been so unsuccessful that re-development is indicated. Re-development of community services in conformity with newer knowledge is at least as important as is re-development of our blighted areas in dwellings.

The GOAL, naturally, is to help as many as possible of the individuals with defects to become self-sufficient. When this is not possible, the type of medical and ancillary care described make other adjustments and placements acceptable to the parents.

The Center has been used by many schools and colleges for the education of students; among these students have been nurses, educators, public health personnel, medical students, physiotherapists, occupational therapists and social service personnel.

Members of the staff have participated actively at all levels, local, state and national, in helping to bring about some of the changes that are taking place. Talks and consultations have been given to several groups and to Boards in this and in neighboring counties.

The most urgent present need is money for direct services to the children and their families.

It is of no value to the patient if money is spent in training personnel and then the facility giving the services is left without money to hire such persons. Similarly, if money is given for research but the knowledge gained does not reach the patient because service programs lack the funds for proper staffing, the purpose of the research fails in fulfillment. Regardless of the amount of money that is raised (publicly by taxation and privately by the innumerable charity drives), like the desert rain, it evaporates before it reaches the ground. The earth remains parched. The focus must get back to the patient and his and the family's problems if we are going to make any inroad on the many facets of human needs. Individuals who volunteer their services to Boards and Councils have a grave responsibility to see that the funds entrusted to them are not expended on a superstructure that employs more and more personnel that have less and less contact directly with the patients. Donors, in general, believe that the money they give is for service. There is an increasing trend among those sophisticated in the field to write off those private organizations that return little or none of the moneys collected to service programs in the community.

In behalf of all the physicians connected with the program, I wish to express our appreciation for the loyalty and devotion of the rest of the staff, Mrs. Jane Sledge, Educational Director; Elizabeth Diringer, Physical Therapist; Marjorie Lund, Occupational Therapist; Mr. E. Walton Kirk, Psychologist, and those previously mentioned, and our Secretaries, Mrs. Reed and Mrs. James, who perform the impossible task of typing for all of us, answering the phone calls, making appointments and tolerating our constant interruptions.

H. E. Thelander, M.D., Director
Child Development Center

July 25, 1963

cc: The Board of UCPA San Francisco
cc: The Board of Childrens Hospital

November 27, 1963

Leopold Lippman, Executive Secretary,
Governor's Study Commission on Mental Retardation,
State Department of Mental Hygiene,
1320 "K" Street,
Sacramento, California.

My dear Mr. Lippman:

For the past eleven years the Child Development Center has worked with handicapped children, the great majority of these children being in the category of Mental Retardation as defined by the late President Kennedy. The work encompasses diagnosis, careful evaluation of the child's abilities, a study of the child's home and environment, counselling for the family, doing habilitation work with the child and attempting to place the child in the proper facility in the community to continue his development. Nearly one thousand children are seen yearly and the staff has learned a great deal about the children, the parents and the community agencies, public and private.

This will be an attempt to condense this experience into a useful summary for the commission.

I. Who sees these children first?

1. Many are recognized at birth by the physician who delivers the baby and by the pediatrician to whom the child is referred.
2. Children who are not recognized at birth because of normal appearance will usually begin to give the parents concern between 18 months and 2 or 2-1/2 years when they fail to start walking, talking and relating normally to the environment. The parent's concern is not expressed as fear of retardation - the questions raised are such as should he not be walking, or talking.
3. Children who escape beyond three years before recognition are then detected in school where they appear as "immature", "not ready for first grade", or fail to learn to read.

It has become evident in our study that if physicians, public health personnel and teachers have an established Center to which these children can be referred regardless of age or financial status - that this is the most successful "case finding" method. We have proposed that a Child Development Center be as integral a part of a Pediatric Department as is the Clinical Laboratory. The Child Development Center is under the direction of a pediatrician with a professional staff consisting of psychologist, social worker, educator, speech audiologist and other consultants, medical and non-medical, as necessary. This is not unlike the Clinical Laboratory in which a pathologist is in charge of professionals in chemistry, bacteriology, genetics, etc.

November 27, 1963

Since it is desirable to get the children early and physicians are consulted first, the logical place for the Center is in a hospital. Doctors are accustomed to send patients to a hospital center for medical services. The other hospital departments are needed for diagnoses, namely x-ray, EEG and laboratory techniques of various types. Children with developmental pathology require more medical care than normal children, a hospital record (in and out-patient) becomes an important part of any study of the child and valuable for any research that will be done. The ratio of such Centers to the childhood population will need to be determined.

II. Have we clues as to which children may be suspect of having developmental abnormalities?

There is a great deal of documentation of this across the country and in many other countries. Certain conditions put children at risk of injury to the central nervous system. Hospitals should maintain for follow-up purposes some type of registry for these cases. For many years an informal card file on such children has been kept and we now follow up children with meningitis, encephalitis, skull fractures, etc., routinely.

The risks may be listed as follows:

Foetal Period - Drugs (thalidomide and others)

infection early (German measles and others), Diabetes, Toxemia, hydramnios, etc.

Neonatal - Hypoxia from any source, trauma, strangulation, hemorrhage, respiratory distress.

Surgical - Anaesthesia - Cardiac arrest, drugs, over or under hydration.

Medical - as noted above (namely infections of central nervous system or toxic products.

Accidents - Concussions, near drowning, fractures, poisons.

If these two procedures, referral to a Center and a risk registry, could be instituted it would not only pick up the victims early but it would greatly sensitize physicians to these hazards and thus tighten up our defenses against such occurrences.

The community agencies have very vague ideas of what is needed and how great the numbers are in need of help of different types. These figures are not impossible to obtain and become realistic to those of us who see these youngsters file past us daily.

The following statistics are for San Francisco:

1. Population 750,000) from Census
2. Children under 20 199,000) Bureau
3. Children on ANC 12-15,000 (Public Welfare)
4. Children in special schools, blind, deaf 2,000 (School Department)

November 27, 1963

5. Estimated on accumulated data - children too severely handicapped for school 200
6. Fringe cases - minimally handicapped, learning problems, deprived, etc. 12 - 15% of children

The greatest unmet needs in San Francisco are:

- I No provision for the 200 (No. 5 above) severely handicapped. Day Care Centers with transportation is needed.
- II For children in No. 4 and 5 above - 2,000 at times temporary boarding places are needed - as during illness of mother - or when mother is called away - or illness of child (often insurance does not cover the situation) and sometimes awaiting State institution admission. There is room in existing Pediatric Departments for such service. In some instances the State should consider contracting with certain hospitals to pay for such care.
- III Children between the ages of 12 and 18 with I.Q.'s 50 to 85 need work training in the school setting and not only academic training. Six years of academic frustrations and failure conditions them to continued failure.
- IV The adolescent slightly retarded child with poor judgment and acting out tendencies often poses a terrific problem to parents. For such children there should be boarding schools where the children learn a trade along with academic work; and also learn self discipline and behavior control. Many would profit from experience in such a setting to the age of 21 or even longer. They might return to the community under some type of guardianship on a trial basis.
- V Guardianship is, of course, of utmost importance and some type of "big brother" or "sister" counsellor throughout life would be helpful to many who lack judgment and discrimination.

If the staff of the Center can be of any further service to you, please feel free to call upon us.

Sincerely,

H. E. Thelander, M. D.

HET:hj

REDEVELOPMENT IN PEDIATRICS

H. E. Thelander, M.D.*

As a part of the discussion on the panel on handicapped and retarded children, I was asked to present the point of view of the practicing pediatrician. This was done in a series of slides. In order to keep the continuity of thought in the written summary the Tables and Drawings are labeled here as "Slides".

SLIDE I. SAN FRANCISCO STATISTICS

Population	750,000
Children under 20 years	199,000
Children on ANC**	12-15,000
Severely Handicapped	2,000
Those in special classes for blind, deaf, halt, retarded.	
Fringe Cases	12 - 20% of all children

Those:

- Emotionally disturbed
- Deprived
- Neurologically handicapped
- Learning problems
- Anomalies and other defects
- Borderline IQs

Comment: Statistics of this nature may be obtained from such sources as the Census Bureau, Public Health Department, School Department and Public Welfare. This fringe group is the reservoir for many of the community problems, the drop-outs, delinquents, neurotics and the plain inadequate citizens. An expensive survey is not necessary and often serves merely to kick the problem upstairs instead of sweeping it under the rug.

SLIDE II. CHILD DEVELOPMENT CENTER

(For diagnosis, total assessment, therapy, follow-through and counseling)

Staffs: Medical: Pediatricians for evaluation and consultants as indicated

* Director Child Development Center, Children's Hospital, San Francisco.

** Aid to Needy Children

Non-Medical: Psychologist
 Social Worker
 Educator
 Speech-Audiologist
 Reading Therapist
 Physiotherapist
 Occupational Therapist

Secretarial

Volunteers

Comment: Children with severe handicaps as well as those on the fringe need a careful medical examination in order to make a basic diagnosis. In addition they need an assessment as to their abilities and disabilities in functioning. The family and environment of a handicapped child needs to be assessed as to its strengths and weaknesses in order to help the child attain his maximum potential. The child, even when handicapped, is a growing organism and his development in all areas needs to be re-assessed at intervals. In infancy and early childhood, these reviews are done fairly frequently in much the same manner as well baby visits have been established. As the child grows older, fewer assessments are necessary. The crucial periods are: at two to three years when the child is acquiring his independent skills, namely walking, talking and toilet training; at six to seven years when he is at the age when the three R's are mastered; at adolescence when he is faced with adult independence and the interference of his handicap with this accomplishment; and finally as an adult desiring to marry, raise a family and hold a job.

In the process of helping these children and their families it became apparent that the needs of the children and the established community agencies did not dovetail. This will be noted below.

SLIDE III. Insert picture.

Comment: A child with defects whether inherited or acquired has more than one problem. Interference in early foetal life may affect one organ more than another but, to some degree, the whole organism is altered. The community agencies and facilities on the other hand have been developed around categories. This makes it impossible to either finance the evaluations properly or to place the children in an optimum learning situation. As examples: Public Health through its Crippled Children's Services will pay for diagnosis and hospital treatment for certain disease categories. This, however, does not help a host of other children with equally great need, nor does it follow through with the necessary counseling, placement or frequent re-assessments; similarly, the School for the Deaf will not take a deaf child with cerebral palsy and the School for Cerebral Palsy will not take a child who also is deaf. The

Mental Hygiene Division has clinics for Child Guidance but it will not furnish a Center with personnel for evaluations or consultations (both much needed). Psycho-therapy as administered in the Child Guidance Clinics is seldom needed. The private agencies have become so enamored with Research, National and International Medical meetings and "Public Relations" (whatever that is) that there is very little money left for service.

Faced with this situation, there seemed only one recourse. The children are indivisible and will continue to come as bundles of multiple problems. The agencies, however, can change. For this change the term "Redevelopment" has been used. It is a term that has been used for modernizing the physical aspects of communities by both mending and by razing and rebuilding.

The rest of the Slides pertain to this need.

REDEVELOPMENT

SLIDE IV. There should be no indigent children.
There should be no discrimination against children
because parents cannot pay.
Federal, State and Local Public Health Agencies
should contract for care at private or University
Hospitals.

Comment: This should be self-evident.

SLIDE V. A diagnostic, assessment and therapy unit as described
under "Child Development Center" should be as essential
a part of a Pediatric Service as are the Clinical Laboratories with a Pathologist in charge of a paramedical staff.

Comment: These Centers should be associated with Hospitals and Pediatric Centers. They should not be in Schools, in Mental Hygiene or in Public Health Departments. The Medical diagnosis is basic. One is reminded of a parallel situation in the case of pneumonia before antibiotics were available. With no therapy other than mustard plasters and steam, the etiological organism was of academic interest only. The acquisition of specific therapies, however, requires greater attention to specific diagnosis. In the field of retardation and handicaps the stage has been reached where specific diagnosis is equally essential. No longer should children with imperfections and impaired abilities be dumped into one classification, "retarded", not even into three, "idiots, imbeciles and morons".

SLIDE VI. The number and types of problems associated with our aging population as well as the changing pattern of

illnesses in children calls for more hospitals exclusively for adults. Programming for handicapped children should be developed in Pediatric Centers.

Comment: This concept will take redeveloping since Hospital Boards, Administrators, Staffs and Accreditation Boards have been habituated to think in terms of four Clinical Departments in all Hospitals with the result that services for children are severely fragmented. There may be a cardiac program in one hospital, a plastic surgical program in another, congenital deafness as a small part of an adult program for the deaf, and so on ad infinitum. In this situation not only does service to children suffer but teaching and research likewise. If all of these services were forced into Pediatric Centers by promoting hospitals exclusively for adults, the habilitation of handicapped children would be enhanced.

SLIDE VII. Diagnosis is not enough. Pediatricians must follow a child's functioning into the home and community and help to rectify the present outmoded and expensive as well as totally inadequate super-structure.

Comment: A diagnostic facility as a part of a Pediatric Hospital Center to which problems of development can be referred with as great ease as they are to a clinical laboratory and without loss of the patient has been a welcome addition to the physicians of the community.

SLIDE VIII. It is essential that we get off the treadmill of:
Surveys
Demonstrations
Pilot Studies
Projects
Grants
and do some constructive, long-term, properly financed community planning for handicapped children.

SLIDE IX. Insert picture.

Comment: In Space science, the astronauts and the nuclear physicists are working as colleagues to solve the problems in this new field; in the health sciences the money for research is entirely out of proportion to the money for services. A lesson from Space Science would accelerate the resolution of some of the health problems.

SLIDE X. Insert picture.

Comment: As Medical Science has evolved there has been a tendency to combine three functions, teaching, research and service, in one individual. Obviously, at present "the dish has run away with the spoon"; Research is prospering at the expense of service and teaching. This picture could be altered rather quickly as follows:

Service programs should be set up in Hospital Centers to meet all the health needs of all the children in a community. Removing children from indigent lists would make this possible. Careful records and observations can furnish many new ideas as well as an abundant amount of material for laboratory research. This could be supplied to a research colleague who could see the number and kind of patients called for by the study and only for the length of time required; Service to the patient would be uninterrupted. Education could be conducted in a similar manner with a teacher accompanying the students to the center. This is now being done by nurses and several other disciplines. In a seminar after the patients have been seen, the clinician supplements the teacher's session and is available to answer questions.

Pediatrics has the potential to take the lead in developing a whole new concept of health care, education and exploration.

November 1963

GLENN M. RENO
[REDACTED]
[REDACTED] [REDACTED] [REDACTED] [REDACTED]

March 15, 1963

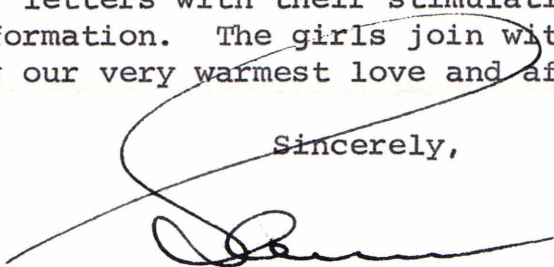
Dr. H. E. Thelander
40 Seafirth Place
Tiburon, California

Dear Jo:

Your greeting by card was most welcome and as usual the card was unusual and very interesting. I am greatly appreciative of your continuing remembrances.

We are looking forward enthusiastically to your coming visit in May and hope that you will give us as much time as possible. Perhaps in the months and time to come we can return your wonderful visits to us by visiting you. On a routine basis we look forward to your letters with their stimulating thoughts and information. The girls join with me in sending our very warmest love and affection.

Sincerely,

A handwritten signature in dark ink, appearing to be 'Glenn', with a long, sweeping horizontal line extending to the right.

Glenn M. Reno

GMR:LE



FRESNO COUNTY GENERAL HOSPITAL

445 SOUTH CEDAR AVENUE

FRESNO, CALIFORNIA, 93702

8/15/63

Dear Jo:

My family had a wonderful time with you at Tiburon. And, I assure you, only a part of that can be credited to Tiburon or even Seafirth.

Bill Ziering, as you can see, is still battering the child batterers. And is getting through. At least around here some of the community conscience is stirring. Even normally dormant "governmental agencies" are turning an ear. However, I hope that his youthful enthusiasm will not be ground into apathy by the erosive forces of "Oh, let's not get too . . . ". He will, perhaps, learn to bend, blink the dust out of his eyes, and snap back to batter another day. Most of his background has been in the academic setting - he tends to be pedantic without the nimble footwork of the practitioner. But his youth and a generally receptive setting work for him. Perhaps an adroit note of acknowledgement from someone like you?

So far as I know, we are all well. Evelyn and the brood are spending the week with friends and Disneyland in the South. Minette will spend a couple of more weeks in San Bernardino. Evelyn and Mark are due home tomorrow or Saturday. In another week, Mark and I plan to be off to the Sierra high country for a few days back-packing. Hard on the old man, all out of training but full of mountain memories which should be shared with the over civilized new generation.

Love,

Mark

ROBERT V. BALFOUR, M.D.
2522 DANA STREET
BERKELEY 4, CALIFORNIA

THORNWALL 3-4704

Dear Dr. Thelander,

I want to thank you for seeing our son James. It is a comfort knowing what to expect - it will help us plan the future.

We have decided to keep him with us - at least for a couple of years.

Again have no idea how helpful you were and we appreciate it very much.

Sincerely
Bob Balfour.

July 18th, 1963

H. E. Thelander, M. D.
Director, Child Development Center
Children's Hospital
3700 California Street
San Francisco, California

Dear Dr. Thelander:

We surely thank you, again, for consenting to appear on DOCTORS NEWS CONFERENCE on August 12th when our topic will be: "After The Birth Defect --"

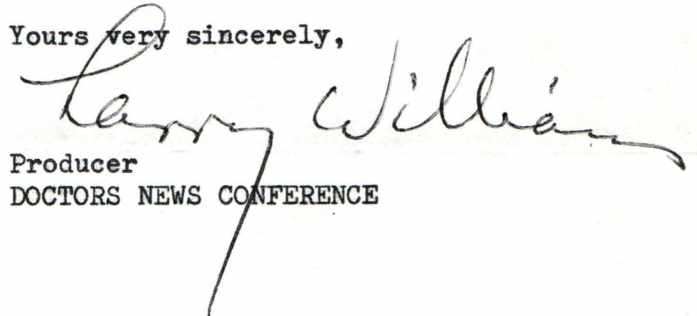
Enclosed are two sets of duplicated material. The blue sheets are specific for this program and carry all the vital statistics. The white ones are general in nature, and usually suffice to answer any questions our participants may have in advance of the program.

However, please don't hesitate to call if you do have further questions, or suggestions.

We are surely looking forward to seeing you again, and the other members of your staff, too.

Every good wish,

Yours very sincerely,



Producer
DOCTORS NEWS CONFERENCE

W/w

Enc. (2)

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FIRESIDE 1-8279

MARY CONWAY KOHLER
[REDACTED]
[REDACTED]

February 21, 1963

Dr. H. E. Thelander
40 Seafirth
Tiburon, California

Dear Jo:

You were a dear to include me in those who received your delightful journal, Around The World In 40 Days. I have read and reread the diary and can visualize each of your many happy experiences. What a trip it must have been.

Of late, I have been seeing quite a little of Dr. Leona Baumgartner, who heads up the human resources side of AIDE of the State Department. Some day when you plan to be on the East Coast I would like to have you meet her. You would have much in common and I believe would enjoy her so much. She formerly was Commissioner of Health for New York City and, according to all, did a superb job in this most difficult of places.

Do let me hear from you, keep well, and know that my thoughts are with you.

Sincerely yours,


Mary Conway Kohler

MCK:kw

UNIVERSITY OF CALIFORNIA MEDICAL CENTER
LOS ANGELES, 24, CALIFORNIA

April 5, 1963

SCHOOL OF MEDICINE
DEPARTMENT OF PEDIATRICS

Hulda E. Thelander, M.D.
3641 California Street
San Francisco, California

Dear Dr. Thelander:

In looking over the last issue of Pediatric World, I was most pleased to read of the honor accorded you as Medical Woman of the Year. Congratulations! All good wishes and they made a fine choice.

Most sincerely,



Margaret H. Jones, M.D.
Associate Professor
Department of Pediatrics

MHJ/fw



transcript publishing co.

50 E. BROADWAY
LITTLE FALLS, MINNESOTA

PUBLISHERS OF LITTLE FALLS DAILY TRANSCRIPT

January 19, 1962

Dr. Huldah E. Thelander
40 Seafirth Place
Tiburon, California

Dear Dr. Thelander:

The Little Falls Daily Transcript's women's department is planning a series of articles about former Little Falls residents who have achieved recognition in their various fields.

We would like to include the story of your successes in this series. We have had inquiries from people who remember you and others, to whom we are writing, and we feel that readership would be very high.

It was very timely, therefore, when Mrs. Frank Dewey came in today with the clipping from the San Francisco Examiner concerning your work with the handicapped.

In addition to your permission to this request, we would appreciate it if you would send your photograph, some information on your Little Falls background, any outstanding recollections of Little Falls or anything you miss in connection with Little Falls or your acquaintances or relatives here.

I assume the information in the article in regard to your work with the handicapped is correct and we could use that information also, saving you a little writing.

I realize this would take quite a bit of your time, but we would be happy if you will give your consent.

Sincerely yours,

Alice Savage

Women's Editor
Mrs. E.A. Savage, Jr.
c/o Transcript Publishing Co.

BIRTH DEFECTS AND INFANT MORTALITY

THE PROBLEM IN SAN FRANCISCO:

According to San Francisco Department of Public Health Statistics, in 1963:

13,893 infants were born.

364 infants died -- 25 of every 1,000 born.

262 infant deaths -- 76% -- were caused by congenital malformations or related diseases of early infancy. In the 1-4 age group, birth defects ranked second only to accidents as the cause of infant death.

174 fetal deaths were recorded - 12.6 in every 1,000 live births.

1,168 premature births were recorded -- 84.5 in every 1,000 live births.

Prematurity was mentioned as a causal factor in nearly 54% of the infant deaths, and in 77% of those who died within 24 hours of birth.

NATIONALLY:

No other birthday -- not even the 70th -- is surrounded by the mortality which surrounds the day of birth. Delivery of a child contains the peak incidence of death in this country, according to Allan C. Barnes, M.D., Chairman, Department of Obstetrics, The John Hopkins University School of Medicine.

The United States has now dropped to 11th place among the leading nations in the prevention of infant mortality. From the 36th week of pregnancy to the fourth week of life represents an eight-week span during which 3.5% of the population dies, and almost an equal number are found to be brain-damaged!

One in every 16 infants born in this country has a serious birth defect. This tragedy affects every 10th American family. Seven per cent of all live births have defects which are evident at birth, or during the first year of life -- 300,000 a year! Less than one half the recorded congenital malformations are detected, or even suspected at birth.

More than 30,000 infant deaths and stillbirths are caused each year by birth defects. Babies who do not die of serious birth defects often have prolonged and costly illness, mental retardation, disfiguring or crippling conditions. Most deafness and blindness are caused by birth defects. Mental retardation accompanies a large proportion of birth defects.

HOW CAN WE ATTACK THIS PROBLEM?

By -- Intensive Research in causes, prevention and treatment.

Education, and the dissemination of knowledge about birth defects. Some birth defects are now known to be preventable. Some can be minimized by treatment.

Better Pre-Natal Care. It has been shown that where pre-natal care is better, the frequency of abnormal births is less.

Better Post Natal Care of birth-defective infants. Dr. Robert E. Cooke, Pediatrician-in-Chief, The John Hopkins Hospital, Baltimore, states:

"Post natal 'prevention' of birth defects is possible. Congenital defects, to a large measure, are manifested some time after birth. Thus there is an important role for the physician . . . in minimizing the effects of birth defects.

"Early detection . . . definite diagnosis . . . appropriate treatment . . . can improve the lot of the birth defective child."

THESE THREE VITAL HEALTH SERVICES ARE AVAILABLE TO CHILDREN WITH BIRTH DEFECTS, AND COUNSELING FOR THEIR FAMILIES, AT THE MARCH OF DIMES BIRTH DEFECTS CENTER, CHILDREN'S HOSPITAL OF SAN FRANCISCO -- AND IN 49 OTHER SUCH CENTERS ACROSS THE NATION SUPPORTED BY PUBLIC CONTRIBUTIONS TO THE ANNUAL MARCH OF DIMES.

S. F. CHAPTER -- THE NATIONAL FOUNDATION-MARCH OF DIMES

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DIVISION OF
SCIENTIFIC ACTIVITIES

OFFICE OF
ADVERTISING EVALUATION

GLENN R. KNOTTS, *Director*

June 12, 1964

*Sketch photo
& forward sheet
inserts
column down
the center
other down
center - cont.
appeal -
plateforme*

H.E. Theleinder, M.D.
3641 California Street
San Francisco 18, California

Dear Doctor Theleinder:

Your criticism of the Warner-Chilcott Mandelamine advertisement in the May 11 issue of The Journal of the American Medical Association was referred to this department which is charged with the responsibility of implementing and enforcing the principles which govern advertising in the journals of the American Medical Association. A copy of these principles is enclosed.

You will note that the Office of Advertising Evaluation is staffed by scientifically trained individuals and is divorced from the commercial aspects of advertising. We strive to ensure the accuracy and propriety of the advertisements in AMA publications; thus, we require that scientific data be submitted to substantiate the claims made for all of the products and services promoted in AMA media. Frequently we seek the assistance of medical experts in determining the acceptability of an advertisement, and such was the case with the Mandelamine advertisement in reference. A large panel of consultants was asked not only to judge the scientific accuracy of the advertisement but also, because it departs significantly from most advertisements in its choice of artwork, the overall acceptability of it.

On the basis of this extensive consultation, the advertisement was accepted. This decision was reinforced by the fact that Warner-Chilcott Laboratories previously had surveyed, in seventeen cities, the reactions of physicians to this advertisement. Almost without exception, the criticisms of the advertisement were based on the length of the advertisement and the obvious expense of it, rather than the artwork.

In addition to the objections we have received, we also have received many complimentary comments, indicating that it is indeed difficult to act as an arbiter of so personal a matter as taste.

We are grateful to you for your interest in the work of this department and assure you that your comments will be considered in our evaluation of future advertisements. For that reason, we are informing Warner-Chilcott Laboratories of your criticism.

Sincerely yours,

Glenn R. Knotts

Glenn R. Knotts

GRK/dh
Enclosure: Principles

RENEWAL APPLICATION

RESEARCH PLAN and SUPPORTING DATA

March 1, 1961 — February 28, 1964

"Epidemiologic Study of Reproductive Wastage"

RESEARCH PLAN

A. Specific Aims —

The general aim of the project is to develop inexpensive and reliable procedures for the prospective study of married women, starting before pregnancy. During the intervals prior to and following conception, current data will be collected regarding factors hypothesized as being related to reproductive loss. In order to determine the outcome of pregnancy, pregnant women will be followed until the termination of pregnancy, and infants will be followed throughout the first year of life.

The methodological conclusions resulting from the project can be utilized by investigators wishing to make prospective studies of reproductive loss, starting before pregnancy. The types of current data to be collected would be determined by the hypothesis which the investigator wished to test.

Before turning to a more detailed listing of the specific aims of the project, it will be useful to summarize the rationale for and results from a pretest started during the first two years of the project. (These results are described in the accompanying "Progress Report".) Mothers who had recently had a first birth and had no history of reproductive loss were selected for an extensive pretest. These mothers were sent an advance letter and scheduled for a first telephone interview. On the first telephone interview, the mother was asked about resumption of menstruation following her previous pregnancy and about recent illness. The second telephone interview, scheduled for a few days following the mother's next menstrual period, asked about illnesses occurring since the first interview and about the most recent menstrual period. The third and succeeding interviews are like the second. At the time of the first missed menstrual period, the mother is asked a more detailed set of questions about illness and interviewed by telephone bi-weekly thereafter. The pretest results suggest that the procedure is feasible with a selected group of mothers who are easy to locate and interview. The specific methodological aims of the project are outlined below.

1. To develop procedures for initially locating and keeping track of married women with telephones.
2. To develop alternative prospective procedures for married women not having access to telephones.
3. To develop telephone interviewing procedures for newly married women.
4. To identify groups of women having an increased probability of reproductive loss and to develop telephone interviewing procedures for such groups.
5. To answer the following methodological questions for each of the groups investigated:
 - a. What is the optimum scheduling of interviews to insure that a minimum number of late menstrual periods and a maximum number of missed periods are obtained?
 - b. For women not found at home at the time of the first telephone call, what is the optimum pattern of future calls?
 - c. What procedures promote continued cooperation in repeated interviews?
 - d. What are the criteria for determining how long a nonpregnant woman should be interviewed?

e. Are there significant differences between telephone interviewers in the amount of cooperation elicited?

f. What are the interviewing costs to obtain a confirmed pregnancy? What are the costs of interviewing during the period of pregnancy?

6. To investigate alternative procedures for measuring factors that may be related to subsequent reproductive loss.

7. To develop procedures for identifying fetal deaths and infants with congenital malformations recognized during the first year of life.

B. Method of Procedure --

For each of the seven methodological aims of the research plan we shall discuss below the background of the problems and the procedures to be used in investigating them.

1. Procedures for initially locating and keeping track of married women with telephones. In the pretest conducted for the project there was a routine procedure for locating the addresses and telephone numbers of women to be included in the study. This procedure was to obtain telephone numbers from Telephone Company publications and to verify all addresses and telephone numbers with the telephone operator before placing a first call. If the family had moved out of the community covered by a given telephone directory, no further information could be provided by the Telephone Company. Additional procedures for determining telephone-ownership status were not explored.

During the first year of the project, considerable emphasis will be placed on developing procedures for determining the proportion of the population having access to telephones. Advance letters will be sent to a sample of about 800 of the various test groups asking for current address and telephone number. (The initial address source will usually be an official record, such as a marriage license or a birth certificate.) This procedure will also yield information about population mobility.

In addition to mail questionnaire approaches to locating married women, either for an initial call or for panel members who move, systematic procedures for checking other sources will be developed and tested. These sources include telephone records, employers, and neighbors living near the woman's last-known address.

For women with a definite address but no telephone in their household, we shall attempt to find out if they have access to a telephone (e.g., in the home of a neighbor). If not, reminder letters will be sent a few days in advance of the scheduled call, asking that such women call their interviewers collect when they have convenient access to a telephone.

All the procedures used will be analyzed in terms of response rates and relative cost.

2. Alternative prospective procedures for married women not having access to a telephone. Over 80 percent of the private households in the San Francisco Bay Area have telephones. Available United States Current

Population Survey data* regarding demographic differentials in telephone service suggest that this proportion (80) percent may also apply to young married couples. The proportion of households having telephones varies directly with income level.

Although it may be possible to increase the proportion of women with access to a telephone by the procedures outlined in Method 1 above, there will still remain a proportion of women not having access to telephones. It may be important to reach this group, since it will be composed primarily of low-income mothers having an increased risk of pregnancy and reproductive loss. It seems important to try to develop procedures for gathering prospective data on this group. One approach is to try mail questionnaire techniques, timing the mail questionnaires to follow the end of each next menstrual period. At the time of a missed period, a more detailed mail questionnaire would be administered. In view of the project's goal to develop inexpensive prospective methods of observation, it does not seem appropriate at this stage to plan personal interviews for women not having access to telephones. The mail questionnaire data will be analyzed in terms of differential response rates within demographic groups and in terms of the cost of the procedure.

In the event that monthly mail questionnaire approaches prove to be inappropriate, procedures will be instituted to learn something of the mobility and reproductive characteristics of the nontelephone group. The group would be followed by mail questionnaires at quarterly intervals. In the event that pregnancy is reported, checks will be made with vital statistics and hospital sources to gain more information about the outcome of the pregnancy.

3. Telephone interviewing procedures for newly married women. Previous experience on the project has involved prospective telephone interviewing of married women who have recently had a first birth. As compared with this group, prospective studies of newly married women might offer two major advantages. First, in long-term studies of reproductive loss, it would be desirable to start with cohorts of newly married women. Second, the proportion of newly married women who will conceive is higher and the time interval until conception is less than for women of higher parity.**

During the first renewal year of the project, it is planned to develop telephone interviewing procedures for newly married women, comparable to those developed for one-parity women. Newly married women with telephones would be sent an advance letter and then interviewed by telephone at monthly intervals about health and menstruation. At the time of the first missed menstrual period, the women would be interviewed more intensively at two-week intervals until pregnancy is confirmed or menstruation resumes. Pregnant women would continue to be interviewed by telephone throughout the course of the pregnancy, and the health status of the child would be followed until at least one year of age.

*Current Population Reports, Series P-20, No. 95, November 9, 1959.

**Cf. "Child Spacing as Measured from Data Enumerated in the Current Population Survey: United States, April 1950 to April 1954". Vital Statistics -- Special Reports, 47(3), October 9, 1958.

In developing the telephone interviewing procedures, alternative approaches will be tested by appropriate experimental designs. (An example of such a design, applied to one-parity women, may be found in the accompanying "Progress Report".)

Some newly married women will be premaritally pregnant. To avoid embarrassing this group, particular care will have to be devoted to the phrasing of the introductory letters and initial telephone interviews. Other methodological questions to be investigated for this group have been discussed under Part 5 (p. 1) of the "Specific Aims" of this Research Plan. The procedure will be analyzed in terms of response rates at successive interviewing stages and in terms of relative costs.

4. Telephone interview procedures for women having an increased probability of reproductive loss. The pretest on one-parity women, described in the "Progress Report", excluded women with a previous history of reproductive loss. Women who have borne one malformed child have a greater-than-average probability of bearing a second malformed child. Similar considerations apply to spontaneous abortions. It may be efficient to oversample such groups of mothers in order to increase the number of cases of reproductive loss. It would be important to pretest telephone interviewing procedures with this group to see whether mothers with a previous history of reproductive loss are reluctant to provide information. The questionnaires and interviewing procedures would be similar to those developed for the pretest of one-parity women. The data for this group will be analyzed in terms of response rates and relative cost.

5. Certain methodological problems common to all of the groups being studied. In developing procedures for prospective interviewing of married women prior to pregnancy, there are certain additional methodological areas which need to be investigated. These areas are listed below:

a. Optimum scheduling of subsequent interviews, so as to minimize the number of late menstrual periods and maximize the number of missed menstrual periods. In scheduling repeated interviews of married women, starting before pregnancy occurs, it is desirable to schedule the interview as close to the ending of the next menstrual period as possible. In case a menstrual period is not reported on that interview, more detailed information will be obtained about illness and other possibly relevant events around the time of presumed conception. Such close scheduling would reduce memory biases. For women having irregular menstrual cycles, very close scheduling would mean that more detailed questions about a presumed conception would be asked frequently during the repeated interviewing. This might lead to reluctance to continue to be interviewed. In scheduling a date for a next interview, account will be taken of the woman's statements about the variations in the length of her cycle, the average duration of menstrual flow, and her more recent menstrual history as recorded in previous interviews. At least two experimental procedures will be randomly assigned for scheduling of next interviews. For example, one might be based on the average length of cycle, and the other based on the maximum reported length of cycle. The experimental results will be evaluated in terms of refusal rates and other difficulties, and in terms of the relative costs of the alternative procedures.

b. Optimum patterns of call-backs for women not at home at the time of the scheduled telephone call. When the first phone call for the initial telephone interview is placed, there may be no one at home to answer. The problem of efficient scheduling of telephone call-backs in order to find the respondent at home needs further investigation. Although efficient scheduling of call-backs is a problem common to many types of surveys, it is of particular importance in repeated telephone interviewing. This is because prospective procedures for studying reproductive loss can be justified only if the unit cost of an interview is kept very low.

In repeat interviews, which can utilize information from previous interviews as to the best time to find the respondent at home, the problem of scheduling call-backs is somewhat more complicated. Since it is not desirable to increase unduly the length of the illness-recall period, we shall seek an "optimum" pattern which would minimize the number of calls within a relatively short time period.

c. Promoting continued cooperation in repeated interviewing. The question of how long to continue telephone interviewing in the absence of pregnancy has yet to be determined (see Part d, below), but it is reasonable to think that this period might be at least a year. In order to determine the outcome of pregnancies occurring a year after the start of interviewing, repeated interviewing might go on for at least two years. There is very little previous experience in this area to guide one in promoting cooperation in repeated observations over such an extended time period. To add variety to the questionnaire, it seems best to concentrate on aspects of family life which have a characteristic pattern of development and which will be of interest to the women who are being interviewed.

For mothers with one or more children, questions about the growth and development of the child appear to stimulate continued interest. For such groups there is a considerable literature and questionnaire experience to aid in the formulation of appropriate questions. For newly married women with no children, guidelines for asking a series of interrelated questions which will stimulate the respondent's interest are not available. These will have to be developed by the project staff.

As another means of promoting continued participation in the project, letters will be sent periodically to the respondents from the Chief of the Bureau of Maternal and Child Health. These letters will thank the respondents for their past participation and emphasize the scientific values of the study. Various forms of letters will be randomly assigned so that their effects on continued participation can be determined experimentally.

d. Development of a rationale for determining how long a non-pregnant woman should be scheduled for interview. For any group of married women being interviewed prospectively, some will never become pregnant -- no matter how long the period of observation. It is clear, then, that criteria are needed for determining how long to continue interviewing in the absence of pregnancy. Some of the relevant factors which must be considered in

establishing such criteria are the following: (1) expected pregnancy rates by age and by varying intervals after marriage, after a first birth, after a second birth, etc.; (2) costs of interviewing until pregnancy occurs, and until the pregnancy outcome is determined, for various periods of observation; (3) the relative risks of reproductive loss in women with short vs. long intervals between marriage and first birth and with short vs. long intervals between successive pregnancies. Information about some of these factors will come from the project itself, while for others it must come from birth interval information. Placing a relative value on obtaining information about "late" vs. "early" pregnancies and incorporating the factors mentioned above in an appropriate statistical model should provide the basis for determining when the interviewing of nonpregnant women should be terminated.

e. Interviewer effects. Unlike household interviewing, where it is usually too costly to assign a subsample of the population to each interviewer, telephone interviewing permits random assignments to interviewers at no increase in costs. With random assignments, significant differences between interviewers are attributable to characteristics of the interviewer, not to characteristics of the persons being interviewed.

During the intensive telephone interviewing carried out during the second and third years of the project, all assignments to interviewers will be randomized. Since the interview procedures themselves will be highly standardized, significant differences found between interviewers can be utilized to improve the quality of the interviewing. They may also provide clues for improving interviewer selection in future prospective studies.

f. Determination of interviewing costs. A crucial element of the prospective procedures being investigated is the cost of interviewing. Once a group of women have been given an initial interview and have indicated the best time of the day to call in the future, a given interviewer should be able to cover a sizeable number of women each month. Calls will be scheduled to follow the ending of the menstrual period. The average cycle length is about a month, and the onset and cessation of menstruation for a given group of women should be randomly distributed over time. Hence, a given number of women can be assigned to a single interviewer, who will make all the initial and subsequent telephone interviews.

As the project accumulates more experience, it will be possible to make estimates of interviewing time and costs prior to pregnancy. The project will also accumulate experience on the costs of interviewing throughout the period of pregnancy. Here, the costs would be slightly higher, since the interviewing would take place bi-weekly for at least the first trimester of pregnancy and monthly thereafter.

In a large-scale prospective epidemiological investigation costs in addition to interviewing need not be high, once the project is underway. Aside from questionnaire editing and other

checks to maintain interviewing quality, there need be no intensive coding or data analysis until the outcome of a pregnancy has been determined. Intensive data analysis would be carried out for all pregnancies resulting in reproductive loss and for only a subsample of apparently "normal" outcomes.

6. Alternative procedures for measuring factors that may be related to subsequent reproductive loss. Numerous factors have been hypothesized as causing congenital malformations and other forms of reproductive loss. Among these are acute illness (particularly infectious illness), injuries, chronic diseases (such as diabetes, heart disease, thyroid disease, anemia, allergy), diet, drugs (including contraceptive agents), operations, personal and family history of previous malformations and other reproductive loss, blood type, cigarette smoking, type and duration of work prior to and during pregnancy, age of parents, and racial and ethnic background. Since reproductive loss occurs in only a minority of pregnancies, it would seem best to keep prospective procedures as inexpensive as possible, with a view to obtaining more detailed information on all unfavorable pregnancy outcomes, together with comparable information from only a subsample of "normal" outcomes. This means that one must be able to decide what data should be obtained currently from the respondent, what data should be recorded currently by the attending physician, and what data can be obtained from the respondent or from medical records after the pregnancy outcome is known.

We will test our ability to obtain information on a selected range of variables as part of the telephone interviews before and during early pregnancy and will also test our ability to obtain information on some (including some duplicate items for checking) through special forms completed by the patient's physician during and after pregnancy. Once a woman has missed one or more periods, has had pregnancy confirmed, and has begun to see a physician for prenatal care, the project will notify the physician that his patient is participating in the study and request his assistance in obtaining certain information. Similar cooperation will be sought from the hospital of delivery and from the physician caring for the infant after birth. At the conclusion of the study the project should be able to categorize certain classes of variables, in terms of the time when and the source from which they can be obtained at least expense, for a given degree of reliability.

7. Procedures for identifying fetal deaths and infants with congenital malformations recognized during the first year of life. Identification of fetal deaths will be made by telephone interview supported, when available, by physician and hospital records, though no special effort is anticipated in this early phase to obtain detailed information on fetal deaths beyond that normally available. Similarly, no special effort will be made to obtain information about the condition of the newborn infant beyond requesting in advance from the attending physician certain standardized data assembled on a study form. Items to be included on this form will be limited in number (focusing particularly on the type and severity of congenital malformations). We anticipate that experience gained in other epidemiologic studies of reproductive loss in the United States can be utilized in the preparation of this form. For those infants who have not obtained adequate examinations from their own physician at the time of birth or at age one, special efforts will

be made to have the mothers obtain a free examination from one of a panel of pediatricians participating in the study.

C. Significance of this Research —

Epidemiological studies of human congenital malformations and other forms of reproductive loss have been of two main types — retrospective and prospective. Retrospective studies start with cases of some form of reproductive loss, such as congenital malformations, and attempt to discover the chain of events preceding the development of the malformation. Retrospective studies are subject to memory biases and to difficulties in defining the population from which the reproductive loss cases have come. Mothers of malformed children, for example, seeking to find a "reason" for the child's defect, are much more likely to remember unusual events during pregnancy than are the mothers of normal children.* When one starts a study with cases of reproductive loss, it is often difficult or impossible to define the population at risk.

Prospective studies avoid these pitfalls by starting with a defined population of pregnant women that is kept under observation to determine the risk that a particular type of reproductive loss will develop. Information is obtained in the same manner for those mothers who will bear a malformed child, for example, as for those who will not. Some studies are prospective only in the sense that it is possible to identify a defined population before observations are made. For example, if the necessary records are available, it is possible to define a population as of some past date and to study its experience with respect to the occurrence of malformations after that date.

The past decade has witnessed a number of prospective studies seeking to identify causative factors in the production of congenital malformations. In particular, the discovery of maternal rubella during the first trimester as a causative factor in congenital malformations has spurred the search for other causative agents, with special attention being focused on virus diseases. These prospective studies have been of two types:

Type I — Studies starting at the time of the first prenatal visit. At that time the mother is questioned retrospectively about events in pregnancy prior to the time of the first prenatal visit and provides further information on succeeding visits.

Type 2 — Studies making use of available medical records. For example, subjects covered by a medical care plan. In this case, data entered in the medical records prior to and in the early months of pregnancy are not biased because the pregnancy outcome is not yet known.

Several representative prospective studies are reviewed and evaluated in a later portion of this application ("Results Obtained by Others", p. 12). Each of the two types we have described above is subject to rather serious deficiencies which we shall consider in more detail below.

Studies starting at the time of the first prenatal visit. The month of pregnancy in which prenatal care is first sought shows a rather wide variability. For live births in California, about 60 percent of the mothers receive prenatal care in the first trimester, about 25 percent in the second, and less than 10 percent in the third. (Three percent receive no prenatal care.) The

*Cf. F. C. Fraser, "Antenatal Factors in Congenital Defects. Problems and Pitfalls". New York State Journal of Medicine, 59(8): 1597-1605 (April 1959).

month in which prenatal care is received is strongly related to the socioeconomic grouping, with the lower social classes tending to seek care at a later stage in pregnancy. Since the relative frequencies of some congenital malformations and other forms of reproductive loss are markedly increased in the lower social classes,* those elements of the population most likely to exhibit congenital malformations seek prenatal care relatively late.

Among those persons obtaining prenatal care in the first trimester, only a small minority start prenatal care in the first month of pregnancy. When women are interviewed at the time of the first prenatal visit about events since the time of conception, most are being asked to remember events over a recall period that varies from six weeks to several months. Thus, recall of events occurring during the first trimester is subject to varying degrees of memory bias, depending on the time of the first prenatal visit.

Recent methodological investigations have indicated the maximum recall periods over which illness can be remembered reliably. Medically attended illnesses can be recalled for not over four weeks. For nonmedically attended illnesses which resulted in some degree of activity restriction, a two-week recall period is maximum, while for minor illnesses resulting in neither activity restriction nor medical attendance, even a two-week recall period is too long.**

It follows, then, that studies starting at the time of the first prenatal visit are subject to severe memory biases for prenatal visits occurring in the second month of pregnancy and later. Memory loss is greatest for the lower income groups most subject to congenital malformations and other forms of reproductive loss. (Although we have used illness recall in our example of memory biases in "prospective" studies beginning with the time of the first prenatal visit, other events dependent on the respondent's memory would be subject to similar biases, depending on the relative severity of the event.)

Studies making use of available medical records. In such studies, illnesses and other events recorded in medical records covering the period of pregnancy are related to the occurrence and nonoccurrence of congenital malformations and other forms of reproductive loss. One possible deficiency in such studies is that the records may not contain all medically attended illnesses. Studies based on notifiable disease reports, for example, are subject to considerable underreporting, because of the failure of some physicians to submit the required forms. (Even if the records are virtually complete, the upper social groups seek more medical attention than do the lower social groups for illnesses of comparable degrees of biological severity. Hence, the lower social groups, in which many types of congenital malformations and other forms of reproductive loss are relatively more common, would have an underrepresentation of illnesses recorded in medical records.)

A second (and possibly more serious) deficiency is that medical record studies exclude illnesses that were not medically attended. One hypothesis is that the abnormalities in the intrauterine environment which cause malformations or are favorable to the continuation of development of defective embryos reveal themselves only as minor illnesses. In this event, studies based only on medical records would miss relevant illness data.

*J. H. Edwards, "Congenital Malformations of the Central Nervous System in Scotland". British Journal of Preventive and Social Medicine, 12(3): 115-130 (July 1958); and F. C. Fraser, "Causes of Congenital Malformations in Human Beings". Journal of Chronic Diseases, 10(2): 97-110 (August 1958), esp. p. 101.

**Based on 1954-1955 California Health Survey data and discussed in: Harold Niselson and Theodore D. Woolsey, "Some Problems of the Household Interview Design for the National Health Survey". Journal of the American Statistical Association, 54(285): 69-87 (March 1959), esp. pp. 80-83.

Thus, each of the two types of prospective studies we have examined is subject to rather serious deficiencies concerning the adequate recording of illness occurring in the early weeks of pregnancy. Prospective studies beginning with the first prenatal visit have varying degrees of memory loss for these early weeks. Prospective studies based on medical records omit nonmedically attended illnesses.

The methodological investigation described in this project proposal would start with samples of women before pregnancy. The procedure would provide a current longitudinal record of menstruation, illness, and other factors of interest. The experience the respondent has gained prior to conception in remembering and reporting morbidity and other factors and the more frequent (bi-weekly) interviewing during the early weeks of pregnancy should virtually eliminate underreporting for the first trimester of pregnancy. It should also provide a more exact assignment of dates of possibly relevant events. This is the primary significance of this research and the characteristic which distinguishes it from other prospective studies in the area of reproductive loss. Of almost equal importance, the procedure is relatively inexpensive.

There are several other significant facets to the proposed research. First, although the pretest placed prime emphasis on getting morbidity data prospectively, modifications to obtain information on other factors hypothesized as being related to reproductive loss will be introduced. Second, the data on current menstrual histories which is being obtained should provide a better estimate of "date of last normal menses" than is usually possible. It should also provide an opportunity to relate longitudinal variations in the menstrual cycle to pregnancy outcome. (In particular, the hypothesis that spontaneous abortion and prematurity are associated with a history of menstrual irregularity could be tested more precisely than has heretofore been possible.) Third, because of the intensive interviewing at repeated intervals which follows any missed menstrual period, the procedure may provide data on the incidence of early spontaneous abortions.

It should be emphasized that the procedure described herein is not proposed as an alternative to present prospective procedures. Once it has received adequate methodological development, it should provide a relatively unbiased and inexpensive means of obtaining current information prior to and in the early stages of pregnancy. It can then be integrated with appropriate procedures developed in other prospective studies.

D. Facilities Available --

This project operates as one of the research units of the Bureau of Maternal and Child Health, Division of Preventive Medical Services, State Department of Public Health, and as such has available a wide range of supporting services in the Department, including statistical services, and tabulating and computing equipment in the Bureau of Vital Statistics and Data Processing. The staff also has access to vital records and other resources of the State and of local health departments throughout California. Expert consultation is available from physicians, microbiologists, nutritionists, and others in the Division of Research and in various other epidemiological study groups in the Department. Expert consultation is also available elsewhere, particularly from the University of California and from Stanford University, in such fields as obstetrics, pediatrics, genetics, virology, epidemiology, survey research methods, and statistics.

The project is being carried out largely in Alameda and Contra Costa Counties, in close conjunction with several other epidemiologic studies (accident, alcoholism, cancer, coronary artery disease) involving the same population of one and one-half million persons. A Policy Advisory Committee representing the interest of the University of California in the two counties has been established to assist the various Department projects. Dr. Corsa and Dr. Mooney are members of a seven-man Research Planning Committee for this Population Laboratory. Local cooperation has been excellent.

SUPPORTING DATA

A. Previous Work Done on this Project —

After a fairly thorough review of the literature concerning epidemiological studies of human reproductive wastage, with particular attention to congenital malformations, it became apparent that previous research into illness and other possible factors occurring in the early weeks of pregnancy was subject to serious deficiencies. These deficiencies consisted of severe memory loss in the case of prospective studies starting at the time of the first prenatal visit and of the omission of nonmedically attended illnesses from prospective studies based on medical records. (There is more detailed critique of previous prospective studies in the section entitled "Significance of this Research", p. 8).

Accordingly, the project began to explore an approach to reproductive loss studies that would be "really prospective" — starting with observations on a selected sample of married women prior to pregnancy. A detailed description of an exploratory pretest is contained in the accompanying "Progress Report".

The pretest, conducted with a group which on a priori grounds seemed likely to cooperate, appears to be remarkably successful. It is doubtful that the methodological problems to be investigated in future years of the project will prove so easy of solution.

In addition to the specific methodological research described in this application, the Bureau of Maternal and Child Health is concentrating on two other closely allied areas. These are:

1. To conduct and support separate but related studies utilizing birth and death certificates and/or hospital records. These have included support of a study of prenatal factors and prematurity at Los Angeles County General Hospital; conduct of a comparative study of data from birth certificates and hospital records in all San Francisco hospitals; conduct of a study of fetal and neonatal deaths, prematurity, and congenital malformations from matched birth and death certificates of all (about 360,000) California births in 1951; and support of a new combined care for the approximately 11,000 persons a year served by the Los Angeles County General Hospital, the Los Angeles County Health Department, the Los Angeles City Health Department, the Long Beach City Health Department, and the Pasadena City Health Department.
2. To develop better exchange of information and of specific plans of research groups now active in the epidemiology of reproductive loss through one or more national professional organizations.

B. Results Obtained by Others --

A most comprehensive recent article on causes of congenital malformations in human beings is by the geneticist F. Clarke Fraser.* He reviews the genetic and environmental factors discovered so far and points out that for the vast majority of malformations no specific causal factor can yet be demonstrated. Fraser describes the varied approaches that are used in studying congenital malformations, including retrospective and prospective studies of events during pregnancy.

Fraser does not suggest trying to use prospective methods prior to pregnancy. He points out the large number of cases that would have to be studied prospectively to obtain enough malformations "unless the cases were selected by some criterion (such as a previously affected child) that would increase the expected frequency. This, on the other hand, would make the sample unrepresentative."** Fraser's objection to oversampling mothers likely to have additional congenitally malformed children is not justified. Modern sampling techniques make it possible to oversample selected segments of a population and to adjust the resulting data so as to obtain unbiased estimates of the appropriate population parameters. The present project would include investigations of the feasibility of prospective interviewing of mothers with a previous history of reproductive loss.

There have been no previous attempts, so far as we are aware (with the exception of the present studies at the University of Pittsburgh), to develop prospective studies of reproductive loss starting prior to pregnancy. As we pointed out in the section on "Significance of this Research", previous prospective studies have been two general types: (1) starting with the time of the first prenatal visit; and (2) medical record studies. We shall review below representative examples of each of these two types of studies.

1. Studies starting at the time of the first prenatal visit

Fern E. French, Louisa P. Howe, Jessie M. Bierman, and Dorothy H. Kemp have described an attempt at "Communitywide Pregnancy Reporting in Kauai, Hawaii" Public Health Reports, 73(1): 61-68 (January 1958)7. The study involved an attempt to get prospectively pregnant women to see their physician early and to return a pregnancy report card to the study. An intensive publicity campaign was used in an attempt to get early reporting of pregnancy.

"About 40 percent of all pregnancies were reported before the twelfth week of gestation, 75 percent before the twentieth week, and 90 percent before the twenty-eighth week.

"First reports of pregnancies came directly from the mothers in 20 percent of the cases, 30 percent from the interviewers, and 50 percent from physicians' records."

Thus, despite an intensive publicity campaign and the availability of pregnancy report forms through periodic mailings, the cooperation of the women themselves was relatively low. This study indicates that one

*F. C. Fraser, "Causes of Congenital Malformations in Human Beings". Journal of Chronic Diseases, 10(2): 97-110 (August 1959).

**Ibid., p. 108.

cannot depend on volunteer reporting of the first missed menstrual period. The article does not state the unit cost of the procedures per reported pregnancy.

Alison D. McDonald has made a prospective investigation of "Maternal Health and Congenital Defect" New England Journal of Medicine, 258 (16): 767-773 (April 17, 1958)7. About 3,300 women were questioned at the time of the first prenatal visit about events in the first twelve weeks of pregnancy. Most mothers were interviewed during the fourth or fifth month of pregnancy. McDonald points out that: "Memory of events was relatively poor for the first four weeks of pregnancy. This was particularly true of acute illnesses..." (p. 768). "...The less dramatic events occurring before pregnancy was perhaps even suspected were not well recalled" (p. 772).

Thus, the two studies we have reviewed illustrate the difficulties with studies starting with the first prenatal visit. Efforts to get women to report the first missed menstrual period have not met with success, and there is great memory loss regarding events in the early weeks of pregnancy. The current Collaborative Project on Cerebral Palsy and Other Neurological and Sensory Disorders of Infancy and Childhood represents a most ambitious attempt to obtain reporting of events during pregnancy, starting with the time of the first prenatal visit. It is expected that it, too, will be subject to biases regarding the recall of events in the earliest weeks of pregnancy, with the extent and direction of the bias varying according to the relative severity of the event being recalled.

2. Studies based on medical records

A. Bradford Hill, Richard Doll, T. McL. Galloway, and J. P. W. Hughes have conducted a typical study of "Virus Diseases in Pregnancy and Congenital Defects" British Journal of Preventive and Social Medicine, 12 (1): 1-7 (January 1958)7. These researchers made use of records from the National Health Insurance Acts, under which employed or insured married women draw benefits for sickness causing absence from work. They studied 129 cases of virus diseases reported as occurring during pregnancy. They found the well-known effect of rubella in early pregnancy but no apparent effect from mumps or measles. The deficiencies of the study lie in the restricted nature of the group studied (employed women) and in the fact that only illnesses of sufficient severity to cause absence from work were included.

Morris Siegel and Morris Greenberg have issued a preliminary report of a prospective study of "Virus Diseases in Pregnancy and Their Effects on the Fetus" American Journal of Obstetrics and Gynecology, 77(3): 620-627 (March 1959)7. This study made use of 89 cases of virus diseases reported by physicians together with a "matched" group of 89 controls. Only 29 of the cases of virus disease occurred in the first trimester. The results of the study are inconclusive because of the small number of cases. The authors recognize that the study was biased because of the selectivity with which women seek medical care for virus disease and because of incomplete reporting by physicians.

The two studies we have described illustrate some of the problems of conducting prospective studies based on medical records. A study currently being conducted by the Health Insurance Plan of Greater New York of 15,000 pregnancies should provide much more information. This study has not been reported in the literature but is described in a mimeographed document: "Pregnancy Study in H. I. P." by Paul Densen and Sam Shapiro, dated October 15, 1958. The possible deficiencies of the study, recognized by the authors, lie in loss of observation through use of non-H. I. P. doctors, in the failure to record non-medically attended illnesses, and in the quality of the medical records themselves.

July 21, 1964

Jerome R. Waldie, Chairman
Sub-Committee Mental Health Services
State Capitol
Sacramento, California 95184

My Dear Mr. Waldie:

Thank you for your letter of July 13th. I have read the preliminary proposals of the committee with great interest. The first and third proposals should be fairly easily implemented. We have conducted our Child Development Center now for twelve years on private funds; it is supported by March of Dimes and Cerebral Palsy, plus hospital funds. Our experience and that of Dr. Koch has certainly shown the feasibility of this type of Center for careful diagnosis and total evaluation. Centers such as ours are qualified now to make an accurate diagnosis and to some degree predict the need for permanent custodial supervision of some type.

Proposal II, the relocation of patients, poses quite another problem. Some of our experiences in placing children in a community may be of interest to you in planning further regarding this part of the proposals. First, retardation is not a diagnosis. Retardates represent a segment of our population and these individuals vary from those severely physically and mentally retarded to those with borderline IQs who are particularly defective in judgment and discrimination. When these latter children reach adolescence they may pose a very major problem to the families and to the community, especially the girls who grow up and are often quite attractive but completely incapable of conducting a home and having children and yet this is what they desire. There are also some children who have minimal physical involvement but are severely retarded mentally, on the other hand there are those who have severe physical involvement but have normal or near normal intelligence which they cannot use because of their severe handicap. Some conditions are detectable at birth, others not until the child is 2 or 3 and fails to develop normal skills, still others are not detected until they enter school. Children do not remain children, they grow up and their problems change with such growth; a retarded young adult is very different from the child he was when he was little.

Retarded children have the same basic needs as other children, namely a home, medical care, training, recreation and religion. It is our experience that defective children are defective throughout, they are small, frail, they have many complications, usually they have visual problems, some have hearing problems, many have congenital hearts and a fair percentage have convulsions. These children are also lacking in immunity, they need a tremendous amount of pediatric care, both medical and surgical, this must be planned for; their life span is probably not as long as a well designed child.

Contrary to general belief, the great majority of parents do not reject the handicapped child. One of the reasons our Center has grown so rapidly is that we do not suggest institutionalization; there of course are exceptions, there are retarded children whose mothers are unwed and reject them and there are some people who reject all their children, these, however, are not in the majority in our experience. The enclosed reports from our social worker came across my desk while I was forming these comments, they illustrate the attitudes, resourcefulness and multiplicity of problems that face the parents and also illustrate the kind of help they seek and need. Parents are not as much emotionally disturbed as they suffer from sorrow and grief and disappointment over having produced a defective child. Those who have had psychiatric breaks are usually the ones who have had previous psychiatric breaks and then produced a retarded child. Very few people in my experience have psychotic breaks only after the child is diagnosed as retarded.

In the third place I wish to comment on the experience we have had with the community resources:

a. Foster homes are not a panacea for long term problems. Foster parents may get tired of the job after a few years, they may get ill or they may die. They often specify that they will only take children up to a certain age. A child's age is not stationary, he does grow older. Certainly a child belongs in a home for the first few years but once he gets to school age he is unhappy without playmates. Planning for recreation, play and amusement is as essential if not more essential than training. Mongols get very unhappy when they go out on the street and the other children will not play with them or they cannot play with normal children. They are happier with their own kind and this can only be arranged if you have groups of them.

It is not good for a child to be moved from one foster home to another. Parents often feel and express "if a foster mother can take care of him why can't I". Parents in general do not like foster home placement if they care at all about their children. The cost of moving a child from one home to another, finding new foster homes, licensing them and inspecting them is considerable.

b. Nursing homes, especially the small privately run ones, have about the same disadvantages as the foster home. It is a very temporary and unsatisfactory placement for a long term problem that has no other solution but permanent care out of his own home. It seems to me that community placement needs a more permanent situation behind the home than that offered by private homes. The Church has done a great deal for the aged and the sick, they like the rest of us, are only beginning to discover the retarded. I believe eventually church homes and private schools that are large enough to have an organization behind them offer a better solution than the small private homes.

c. The Child Guidance and Psychiatric Clinics unfortunately are not always helpful although individual psychiatrists have been of tremendous help. Psychiatrists like physicians in general have had very little or no training in normal growth or development or in childhood neurology. We find that few people realize that a retarded child can become emotionally disturbed. Most psychiatrists approach the problem as if "being emotional" it cannot be retardation. Very few psychiatrists seem to know that organic brain lesions can produce very bizarre behavior. We have "hoppers", "twirlers" and many varieties of bizarre behavior which are exact replicas of experimentally produced symptoms in monkeys; these do not respond as do emotional problems.

I hope someone at the State level discovers that money is spent on everything and anything but direct service to children and their families. The voluntary health

agencies have been rather remiss in helping. We have been able to get help from The March of Dimes and Cerebral Palsy for our work. The cost of running a Center is well known to us. In 1963 we processed 374 new patients. This and the follow up of old patients represents a tremendous number of visits. The budget for last year was \$_____.

In addition to difficulty in homes the communities are not geared to the education of these children. In San Francisco we have about 200 who have been rejected by all the schools and we have had no day care placement for these children. We finally opened up a recreation program at the Center for Recreation for the Handicapped. (Recreation incidentally is another neglected area).

The schools are too academically minded to help the children. The children need to learn through play as much younger children do. When the years from 12 to 18 are spent in academic settings, the youngsters are discouraged and have lost all confidence in themselves. In a play situation they may perform beyond expectation.

The existing community agencies have a great deal to learn and many adaptations to make before the children can be relocated satisfactorily-.

Sincerely,

H. E. Thelander, M.D.
Medical Director
Child Development Center

HET:ar
Encl.



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July 23, 1964

TO: H.E. Thelander, M.D.
Children's Hospital

Estimated current yearly operating costs for
entire Child Development Center area:

Jane Sledge	\$	[REDACTED]
Helen Jamies		[REDACTED]
Anneliese Reed		[REDACTED]
Gladys Kassebaum		[REDACTED]
Marjorie Lund		[REDACTED]
Elizabeth Creamer		[REDACTED]
Gertrude Saxton		[REDACTED]
Barbara Holden		[REDACTED]
Margaret Tunney		[REDACTED]
	\$	50,808.00

Benefits	5,080.00
X-Rays, Lab tests, etc.	3,000.00
Speech & Hearing	1,200.00
Supplies	1,150.00
Miscellaneous (telephone	1,050.00
etc.)	\$ 62,288.00

Overhead (United Cerebral	
Palsy 10%, Nat'l Foundat-	
ion-8%)	5,606.00
	\$ 67,894.00

cc: R.C. Densmore
L.B. Malkin

KRON-TV
THE CHRONICLE PUBLISHING COMPANY

HAROLD P. SEE
VICE PRESIDENT, BROADCAST DIVISION
AND GENERAL MANAGER

August 25, 1964

Dear Dr. Thelander:

We wish to thank you for your contribution to this station's programming in the public interest through your appearance on "The Problem Child," which was broadcast on Sunday, August 16, at 12:30 PM as part of our YOUR CHILD AND YOU series.

We are always pleased to cooperate with persons who can convey expert knowledge to the public through the medium of television.

Very truly yours,

Harold P. See
/s/

Dr. H. E. Thelander, Director
Child Development Center
CHILDREN'S HOSPITAL
3700 California Street
San Francisco, California

HPS:fk



IDAHO DEPARTMENT OF HEALTH

TERRELL O. CARVER, M.D.
ADMINISTRATOR OF HEALTH

NAMPA STATE SCHOOL

BOX 47

NAMPA, IDAHO

TEL. 466-3588

8 September 1964

Hulda E. Thelander, M. D.
3641 California Street
San Francisco, California

Dear Doctor Thelander:

I want you to know how delightful it was to have you with us, and to thank you for coming as a guest in our graduate training program.

I am enclosing a slide which I am very sure came from your collection and which I think you may want to have.

I am wondering if you have at hand any concentrated data on the business of child abuse. I have been asked to talk on this subject to an AAUW group in this state, and somehow I don't seem to have any material on this subject at hand, except what is in my mind.

Again, many thanks for your presence, and I hope that when ever you come this way again you will let us know, because Katie and I both need to visit with people from the outer spaces.

Sincerely,

Erwin C. Sage, M.D., M.P.H.
Superintendent



anyone put your hands on a couple of references I think one was in AMA & I in a pub. archin last year. T. will be back.

The Battered-Child Syndrome
JAMA July 7 - 1962

Vol 181, no 1 page 105-

Henry Kempe et al

The Problem of the Battered Child.

Theodore P Fundt.

Practical Pediatrics. pp 426

April 1964.

The physically abused Child
Katherine Bain

Pediatrics - June 1963 pp 895-

The Pediatrician and the Young Child

Subjected to repeat Physical Abuse

Editors Column Paul V. Woolley

J. of Ped. 62 no 4 - pp 628

Medical Economics - Aug 24 - 1964
pages 62 to 75

REPORT FROM THE BIRTH DEFECTS CENTER
CHILDRENS HOSPITAL, SAN FRANCISCO

January 1, 1964 - June 30, 1964

NEW PATIENTS TOTAL 149

by months:	January	26
	February	22
	March	35
	April	21
	May	23
	June	22

COUNTIES REPRESENTED

San Francisco	75
San Mateo	23
Marin	11
Sacramento	5
Napa	5
Santa Clara	4
Contra Costa	3
Santa Cruz	3
Yuba	3
Solano	3
Monterey	2
Sonoma	2
Humboldt	2
1 each from 7 other counties & Nevada State	8
Total	149

TYPES OF ANOMALIES SEEN:

I Central Nervous System as follows:	
Minimal neurological deficit with learning problems	38
With seizures	4
Microcephalus	3
Hydrocephalus	1
Spina-bifida	1
Total	47
II Anomalies including or involving special senses	
Speech and communication problems including aphasia	12
Deafness	4
Visual Handicaps	4
Total	20
III Multiple Small Anomalies with general stunting (ears, thumbs, webbing, etc.)	29

IV Anomalies of G.I. tract		
Including Oral cavity		
Cleft palate		2
Choanal atresia & swallowing		1
Agenesis left upper & lower jaws		1
Esophageal fistula		1
Imperforate anus		2
	Total	7
V Glandular Anomalies		
Hypothyroid		5
Genital or suspect		3
Cystic fibrosis		4
Growth retardation pathology		2
	Total	12
VI Major Anomalies of Limbs		
Upper		4
Lower		1
	Total	5
VII Mental Retardates		
Mongols		5
Normal chromosomes & chemistries		6
	Total	11
VIII Hematological		
Sickle Cell (with hemiplegia)		1
Anemia with retardation		1
	Total	2
IX Post German Measles Syndrome		
(With deafness, visual handicap and cerebral palsy athetoid)		1
Congenital cerebral palsy, cause unknown		1
	Total	2
X Slow Developer		2
XI Post Central Nervous System Disease		
Meningitis and Encephalitis		12

The above statistics reveal that only half of the patients of the Center come from San Francisco. The next greatest number come from the abutting counties and then there is a scatter of patients from the remote areas. The source does not reflect only ease of access; referral depends also on the availability of diagnostic and treatment facilities within or near a community. California is well supplied with physicians including pediatricians. The State has an excellent Department of Public Health; a good Mental Hygiene Division and a study commission on Mental Retardation. These activities stimulate interest, spread education and in some manner touch upon most of the children with defects and their families. In the past 6 months I can recall only one child who has

been hospitalized and paid for entirely by the March of Dimes. In most instances hospitalization has not been necessary and when it has been so the cost has been met privately, by insurance or by Crippled Children's Services.

The type of problems encountered in the Center warrant some comment. The largest group consists of children with lesser neurological deficits manifest primarily in learning problems. As early as 1954-57, the Center staff began calling attention to this problem and the large number of children involved. Largely through the efforts of parent groups legislation was passed last year making provision for special classes for these children. Closely related to this group are the children with more marked handicaps especially in speech, hearing and vision.

The next largest group, namely the children with multiple small anomalies, has interested the staff very much. Attention has been called before to the difference between the child who in our terminology is "well designed" but gets hurt and the child of poor original design. It is our belief that this is a very basic observation of human development and one that has important ramifications. In the past few months Helen Pryor, M.D. has joined us one or two afternoons a week to make anthropometric measurements. She has had wide experience in this field. To her gross measurements will be added our observations on detail of development in each case. There is a great deal to learn as to the role of fetal environment and of genetics in this "design".

There is close cooperation with the Center and the "Recreation for the Handicapped" organization and also with the various religious programs for the children with defects. Programming to meet all the basic needs of children with defects and their families therefore is emerging. These basic needs include home, medical care, education and training, recreation and religion. The handicapped child in addition may have special needs for equipment (wheel chairs, crutches, etc.) and transportation.

The Center has become a part of Pediatric diagnosis in the Hospital; in organization not unlike that of the clinical laboratories. In the latter a physician is in charge of a non-medical professional staff such as bacteriologists, chemists, etc.; in the Child Development Center a physician is in charge of non-medical professionals in the child field such as psychologists, speech audiologists, educators and social workers. Physicians and educators particularly are grateful for this type of study of the child's abilities and for the assistance the Center can give to help the child and family find a suitable role for the youngster.

The prevention of Birth Defects must be attacked vigorously. This will be far more difficult than any immunization procedure has been. The Academy of Pediatrics through its Child Development Center is making moves in this direction. I am sure the National Foundation is also planning attack in this area.

We are very grateful for the Foundation's support and interest.

H. E. Thelander, M.D.

UNIVERSITY OF CALIFORNIA
SAN FRANCISCO MEDICAL CENTER

SCHOOL OF MEDICINE
OFFICE OF THE DEAN

February 8, 1963

H. E. Thelander, M. D.,
3641 California St.,
San Francisco 18, Calif.

Dear Doctor Thelander:

Another year has passed and with it another year of your active participation in the affairs of the San Francisco Medical Society. Good relationships between the medical school and the medical society must always depend upon the good offices of individuals such as yourself who give of your time and talent to both.

In San Francisco we are most fortunate. You may be interested to know that over 200 members of the faculty of the School of Medicine take an active part in medical society affairs and some 400 members of the medical society are members of the clinical faculty. This overlap of interest by so large a segment of our professional community has been most rewarding to the School and, I believe also to the Society.

For your part in this, the School of Medicine is most grateful. In serving on the Hearing Center Committee of the San Francisco Medical Society during 1962 you made an important contribution to our profession. I do hope you will continue to find time for this valuable work which is so very necessary and so very much appreciated.

Sincerely yours,



J. B. deC. M. Saunders, M. D.
Dean

JBS:fc

May 22 1963

Children's Hospital Expansion Plan

Plans for a \$5 million expansion of Children's Hospital were announced yesterday by Chairman Roger Lapham Jr.

The announcement kicked-off a fund drive which is unique in that, until November, it will be limited to the immediate hospital "family," such as directors, trustees, doctors and hospital employees.

NEW UNITS

The building program will include four major segments. The two most notable features will be the seven-storied research and outpatient unit frontin on Sacramento St., and the construction of a new east wing addition.

The research unit will include the child development center, a service unique in the Bay area; the pediatric and adult outpatient clinics; the child guidance center and the youth clinic, as well as all research programs.

Lapham said that the hospital is fast becoming one of the top research centers in the West, and that there are presently 20 projects active in the hospital involving \$500,000 and 47 persons.

EAST WING

The new east wing addition, to be built on the present parking lot, will include 44 patient rooms, the dietary department, private meeting rooms, volunteer facilities, and a 1,000-seat auditorium seating 270 persons with ground floor level access from the street.

The problem of parking will be partially solved by a ground-floor garage in the research wing.

The hospital board is at-



HOW CHILDREN'S HOSPITAL WILL LOOK
... Mrs. Ross Beales and Roger Lapham Jr. in-
spected model

tempting to purchase private property directly opposite the hospital's ambulance entrance on Cherry St. and California for the building if a parking garage.

Occupying the southwest tip of the present property will be a new West Wing which will include emergency and examination rooms, and the doctors' lounge and consultation rooms.

Lapham said that with Hill-Burton State and Federal Aid, National Institutes of Health Grants and mortgage loans, nearly half the needed \$5,000,000 were already on hand.

"And we hope to raise half of the remaining \$2,900,000 within the hospital family," he said. "Then, in November, we will have one brief but highly intensive public campaign for funds."

Conquering Hidden Handicaps

By CLAIRE LEEDS

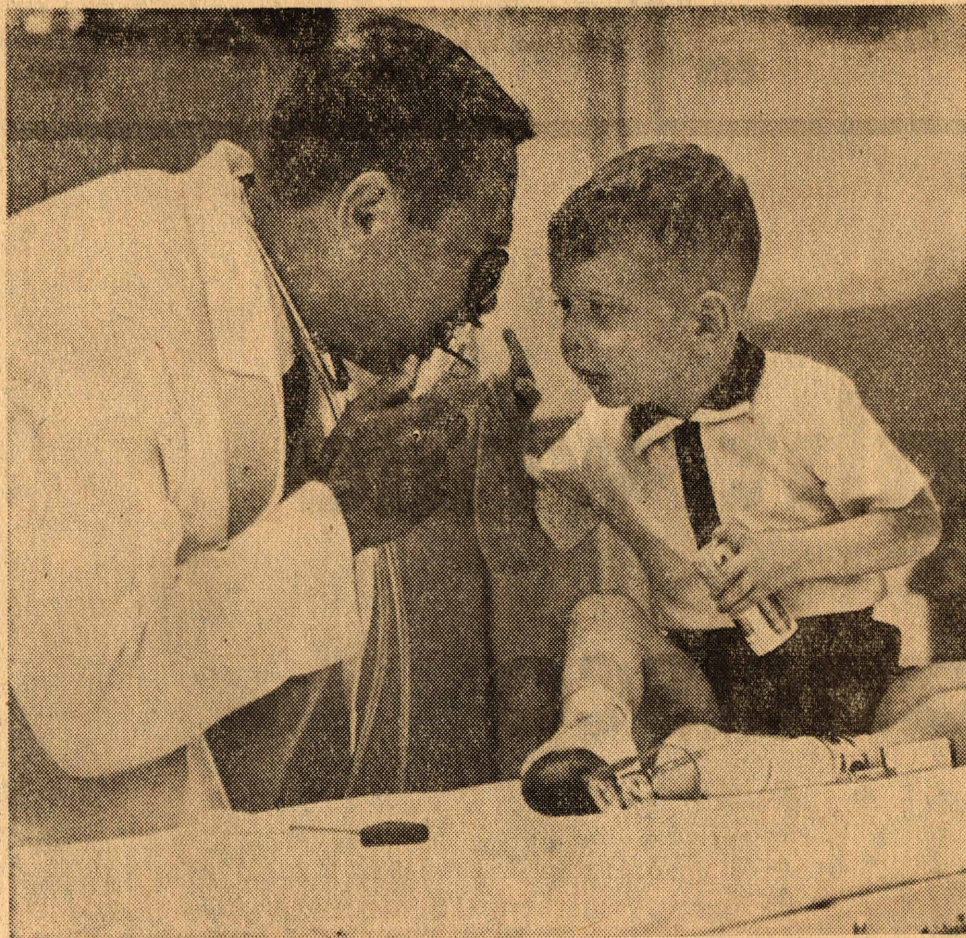
The heartbroken mother of a baby born with a severe handicap hungers for reassurance. She is haunted by a thousand unanswered questions. Where can she find help?

The answer, in northern California, is the 18 month old Birth Defects Center at San Francisco's Children's Hospital, financed by the National Foundation-March of Dimes.

This remarkable outpatient clinic, part of the larger Child Development Center at Children's Hospital, reflects the philosophy of its director, Dr. Hulda E. Thelander.

The dedicated pediatrician, one of The Examiner's 1962 Distinguished Women, says: "The birth of a child with defects is a sad event. It is a sorrow which continues unless the parents can also discover the child behind the handicap."

To "discover the child," she believes, takes the most thorough kind of diagnosis not by



WHO'S BEING EXAMINED AT MARCH OF DIMES CLINIC, DOCTOR OR PATIENT?

Doctor is Paul Wilson; patient young Saul David Robin, born with multiple handicaps

one physician, but by a team of specialists.

Can the child be helped by surgery? By

psychological testing? By special therapy and education... or a combination of these? How can

counseling guide his parents toward a better understanding of the child's potential and

limitation. The Birth Defects Center offers all these services to handicapped children and their grateful parents in a single setting.

Since Nov. 1961, the center has treated 550 patients from infants to age 18. Their disabilities ranged from such major birth defects as enlarged skull and open spine to "subtle abnormalities of the central nervous system," Doctor Thelander reports.

The latter are a source of special concern, she notes, because they often are not detected until the child is in school.

"These are children with learning problems (other than mental retardation). Without help, they may become truants, drop-outs, youths with serious behavior problems."

These "hidden handicaps" may not become obvious until the child falls hopelessly behind in subjects like reading and arithmetic, according to Doctor Thelander. Her goal: A system of early screening that will bring them to light before the child reaches kindergarten."