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Focusing on community service programs for the cerebral palsied, organizational patterns considered are program implementation, a state advisory and evaluation board, a program committee, continuing staff education, staff training at state schools for the retarded, training sub-professional volunteers, state legislation, and financial support. Various patterns of care are discussed and include a high risk mothers program, interdisciplinary clinics, rural satellite centers, the Rochester Rehabilitation Complex, agreement with the Visiting Nurses Association, the development of dental services, home service programs, day care programs, plans for a residential care facility, and therapy program. Prevention and early care, infant, pre-nursery, and nursery programs, and services to parents of preschool children are presented as aspects of early care. Adult and teen programs described are the small business enterprises program, sheltered workshops, continuous care for the severely handicapped, a work activity center, and the evolution of an activities program. (RJ)

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HIGHLIGHTS OF SERVICE PROGRAMS

UCPA Affiliate Presentations

at

1968 Regional Hearings

MEDICAL AND SCIENTIFIC DEPARTMENT

United Cerebral Palsy Associations

66 East 34th Street

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## P R E F A C E

*Affiliate responses to the Regional Hearings pinpointed service priorities which have been summarized in the booklet, "The IHF Plan - The Individual with Cerebral Palsy and His Family." Copies have been distributed to all officers and affiliates of United Cerebral Palsy Associations.*

*Another valuable product of the 1968 Regional Hearings proved to be Special Presentations of Community Service Programs. These demonstrated unique or particularly useful approaches to service by affiliates in every part of the country.*

*These Highlights have been summarized and are distributed as an exchange of information between service units. They are not offered as the way for a service to be organized, but as thought-provoking ways in which an affiliate has grasped opportunities available. While it may be useful to duplicate some of these approaches in other locations, all of them will undoubtedly serve to stimulate other dynamic service approaches.*

Medical and Scientific Department  
United Cerebral Palsy Associations, Inc.  
1969



## IMPLEMENTATION OF A PROGRAM STUDY

Presented by  
Margaret Schilling, ACSW, Executive Director  
UCP of Greater Detroit, Michigan

During 1962 - 1963 United Cerebral Palsy Inc., United Community Services of Detroit, and the United Cerebral Palsy of Detroit jointly entered into a survey of services for the cerebral palsiad. Originally it was planned that this was to be concerned with the services of the affiliate program. However, when United Community Services agreed to co-sponsor the study, this broadened the project and we were able to involve many other agencies. Twenty-seven agencies participated in the original study. Not all of them registered cases, but many of them gave service to the technical advisory committee. As a result of the survey, there were eleven recommendations. What has happened to these recommendations in the span of the last four years is as follows:

1. The first recommendation was that there be created an on-going technical advisory committee in order to profit from the communication and cooperation which had come about as a result of the study. This was done as soon as the report had been accepted by United Community Services and the "Cerebral Palsy Counsel" was organized. This has had a fluctuating membership of between twenty and twenty-five people, most of whom are agency executives, but who are on the council as a result of their particular disciplines, rather than because they represent a given agency. For example, there are pediatricians who happen also to be associated with an institutional program and social workers who are also directors of programs, but they represent their professions rather than the agency. The council met actively, monthly for about two to two-and-a-half years. Now it meets on a quarterly basis, since most of the major problems which we undertook to solve have reached some solution. The council has been most effective as will be seen later in the other recommendations in implementing some of the programs.
2. It was recommended that we establish a central registry for cerebral palsy. A very complete study had been done on 275 patients by the Visiting Nurses Association, and it was hoped that they would continue to do this. Unfortunately the costs were too exorbitant. They had spent a considerable sum on the original case load and did not feel that they could continue to see the remaining four thousand patients on the registry in the same detail. However, the roster has continued to grow. It has been limping along in the last year, due to the very poor and inadequate supervision and due to the inadequacy of the director. Beginning September 1967, we obtained a forceful and very dynamic young woman who is now running the cerebral palsy information and referral center of which the roster is a part. There has been a clearer division of authority between the roster and the other services of information and referral. The cerebral palsy council has assumed the responsibility for getting the roster into better shape, for widening the base on which agencies are participating, and for initiating with the director many calls to non-registering agencies so that we are seeing a considerable increase in names coming into the agency. All of this data is now well documented. It has been put on IBM cards at a nominal cost since Good Will Industry had the data processing machines and wanted to use their trainees in getting this tabulated. We are now registering close to 6,000 patients with no duplication. The diagnosis is coded, as well as

the educational achievement, training, employment, living arrangements, etc. The roster has been used on some occasions for very dynamic program items; for example, to find all the teenage youngsters living in the given area who might participate in the recreation program; or, to find all of the patients who had once been referred to the Division of Vocational Rehabilitation and who are not employed now. Both of these served to document the need for further programming in certain areas.

3. The third recommendation was to establish an information and referral service for cerebral palsy patients and their families, which would be a resource for providing better utilization of existing services and for gathering data regarding the need for additional services. This also was created as soon as the study had been completed and has been attached to the United Cerebral Palsy of Detroit. It has some extremely good values. Its efficacy varies in intensity, again depending upon the adequacy of the person who is running the program. This is utilized mostly by non-organized sources such as, the relatives of the patient, or a service club or a concerned group of volunteers. The published brochure on this subject is distributed quite widely and brings in new requests. There is no uniformity of referrals. We may run as high as six or ten in one day, and none for a week. We do feel, however, that this is widely used. The service has been copied by other affiliates and, as we progress now on a firmer basis, it seems to us that this will be one of the services with increasing impact. It is quite interesting how many people call us now asking for information about services throughout the United States rather than just the Detroit area as they recognize that there is one place where they can get data. We are accumulating a vast amount of knowledge, a good resource file, which eventually should have impact on community planning. Interestingly, we were the first health agency to break away from the Central Community Information Service. Subsequently, the mentally retarded have started their own registry, and we understand that Michigan Epilepsy will shortly do the same thing.
4. The fourth recommendation was for centralized follow-up service for all patients with cerebral palsy to supplement previous recommendations above. This has not been done, nor will it materialize in the foreseeable future. It is done on those patients who are known initially to the IRR (Information, Registry and Referral) service, but the other agencies who register patients prefer to do their own follow-up and do not want interference, as they call it, from the informational referral service. There are some evidences that long-term planning is beginning to be thought about by agencies who have not considered this in the past. This is probably coming about because of the studies we are doing on a statistical, not a name, basis for registry. It has been used to define some unmet needs. For example, Plymouth State Home and Training School was looking for a group of youngsters who might come into their Habilitation program, and the Detroit Orthopedic Center used the roster-registry to find their patients who are not now under care. However, the follow-up service probably remains one of the weaker aspects of the project. Its strength depends on the quality of service of the agency making the referral.

5. It was recommended that some thought be given to possible decentralization of some aspects of service. This had been discussed in detail as the board evaluated the survey and talked with UCS. It seemed to us that this was too costly a process. The recommendation was not accepted or approved by the board or by United Community Services. We did not have sufficient staff to spread it around, nor did we have the kind of facilities in the communities that might be utilized. The one that looked possible, the Easter Seal Society in Western Wayne County, found itself unable to offer us any space. Therefore, we turned in another direction and began to work with the tax supported agencies to establish pre-schools in metropolitan Detroit. We have been most successful in this, and by the fall of 1968 there will be nine nursery schools scattered in a wide geographical area. In addition, we have encouraged outpatient departments of hospitals to offer more therapy to individuals with cerebral palsy, and now this is much better than it was before. In fact, there are now nine hospitals in the area with good cerebral palsy clinics to which a patient can be referred for therapy. The Easter Seal Societies in two areas, Detroit and Macomb County, have also enlarged their services and are doing an excellent job of giving therapy to the patient in the local area. This poses some problem in sharing other responsibilities beyond the therapeutic level, but these can eventually be worked out. We are presently retaining a small group of children in a preschool program, purely for demonstration and teaching purposes. This will grow even smaller as time goes on.

One of the chief reasons for suggesting the decentralization was the problem of transportation. We have now ceased transporting children, and consequently children are brought directly to the center by their parents. They arrive in a much shorter time, the parents have less waiting, and car pools are working out a much better means of getting the children in for care. No children dropped out of the program because of transportation. We are again impressed that if you put the problem back in the laps of parents, they frequently can find better solutions than we could work out for them from an agency point of view.

6. It was recommended that some priority be given to the need for early identification and referral to agencies in the development of a more adequate program for infants and their families. The cerebral palsy council accepted this as one of their major responsibilities. Working through their medical professional committee, they have spoken to pediatric sections of the various county medical societies, have written and formulated a pamphlet for physicians which has been distributed to all doctors, osteopathic surgeons and nurses in the tri-county area and are planning a very excellent exhibit at the next Michigan Medical Society. The nursing division of public health departments have been actively engaged in trying to find children, and identify them early and get them into care, not only to our agency, but to all others in the field. Visiting Nurses Association has been extremely active in this area. Unfortunately the Maternal and Child Health federally founded agencies came into being without any recognition of the services we have to offer. This is equally true of the program at Children's Hospital where there is now a clinic for the multiple handicapped. There is now much we can do about this in terms of the political structure which brought these into being. We work continuously utilizing our contacts with the social service departments of various hospitals and clinics where these children are seen in order that they get into our agency for on-going care.



It is interesting to note the change in our own case load as we have begun to recognize our responsibility for this much-younger age group. Where, a few years ago, it was remarkable to see a child under age four, on our last statistical analysis a large percentage of our children were under 18 months of age. In fact, at the moment our dentist claims we have so many young children that he does not see a need for continuing quite the level of previous service. Recently most of the children seen do not have any dental problem nor will they have until they are two-and-a-half or three years of age. It has been quite interesting to watch the changing focus in the way we manage these youngsters. We continue to see them initially in a group program, with their parents in a counseling session at the same time, and then, once the therapist has become acquainted with the child, some individualization or smaller groups for care. We are moving now in September, 1968, into regular home visits on all of these youngsters in order that we may be doing some therapy with the parents in the home. This will be more of a continuum service than we can give when we see them only at the center and need to spend such a long period of time in getting the baby acclimated.

7. The seventh recommendation was that we recognize more clearly the problems of the severely handicapped and their family. The severely handicapped and retarded child is now getting good care both at the Plymouth State Home and Training School through the Habilitation Unit, through the Activity Centers of Detroit League and Good Will Industries and through the day care centers of the Michigan Association for Retarded Children. We feel that this later increase in service came about because of the program which UCP of Detroit conducted proving that these youngsters could be handled in group activities. We are now seeing children integrated in small units, two or three at a time, into the regular day care program with extra additional help being given.

For the non-retarded there is almost nothing being done for the severely involved child. It is still necessary to send this child outside of the state to get care, unless we can persuade the family to move into Ypsilanti. If they can, then these severely involved educable children are being cared for at Rackhama School on a day care basis. This is one of the gaps in service in Detroit.

8. The eighth recommendation urged that we recognize need for expanding services for teenagers and adults. In the vocational field, this has been improved remarkably. The Detroit League for the Handicapped now sees many teenagers for a one-month work evaluation in the summer, sharing their findings with the school when these youngsters are thirteen and fourteen years of age and establishing more realistic goals. Jewish Vocational Bureau has an excellent eighteen-week evaluation program for young adults. It is now moving into a new project, has been given a \$450,000 grant to build a new facility. They will take our referrals with no problem. The Executive Task Force created under UCS has participation by agency executives, the Division by Vocational Rehabilitation and the United Community services. This is an excellent program, and has a wide range of participation. It can program for almost any activity, if the group really decides there is a need. The services offered by the Executive Task Force have changed the face of much of the vocational work in Detroit. As a result of this impact, senior high schools are slowly awakening to their responsibility. We would

like to begin to work with the vocational counselors in the junior high school level, but this poses some real problems and we need to think this through carefully since it will take time, travel, money and staff. In order to be sure that we are planning correctly, we have recently asked the regional director of vocational rehabilitation to come on our board of directors, and he has accepted this appointment. We feel that with his help, we can plan much more intelligently.

9. The ninth recommendation was for additional resources for recreation and group activity. May I say that this was a complete flop under the cerebral palsy council. The YMCA tried it, the YWCA tried it, group work organizations got behind it, but it just never got off the ground. There have been perhaps three or four well-planned activities with good publicity and with advance notification sent out to parents and to teenagers. In one instance, eleven people came, and in the other two, three or four. It is obvious, that no group work agency either understands how to get the patient there or has access to the patient in such a way that the family will bring them to the recreational facility. Consequently, the Detroit League for Handicapped is about the only organization programming for the young teenager in a group activity, and they are doing this largely through personal hygiene, group work counseling and some recreation tied to this. Since we could not seem to get this program going with voluntary agencies, we turned to the tax-supported agencies. The UCP executive director spent hours in working with the director of parks and recreation, city engineers, council members. They have designed, and are building an excellent facility for handicapped people. It is not as centrally located as we would like to have it, but it has a beautiful setting on the river in the eastern part of the city. It should be ready for occupancy in May, and will be available to all kinds of handicapped people. UCS did create a committee on overnight camping, and the school board opened camperships this past summer to 24 children in each two-week group. Day camps are fairly good. Boy scouts and Campfire Girls now accept moderately handicapped. By getting some of our fathers to act as troop leaders, we keep our children in some of these programs.
  
10. The tenth recommendation was that agencies give greater service to school programs. UCP of Detroit has worked very well with varieties of schools in school visits, developing techniques of bringing a clinical team out to the school. We have not found that other agencies are willing to follow this pattern. We do get excellent cooperation from the departments of special education, particularly in Detroit, where preschools were started because the cerebral palsy council underwrote some of the original cost. But in terms of actual school programs this has come not through any impact we may have had but from the school systems; for example, Oakland County, which voted extra mileage some years ago, has tremendously good programs with classes for all kinds of learning disabilities in children. Schools for any exceptional child leave much to be desired in Macomb County and are only fair in the Wayne County area. This was not a successful experience for our agency, but we have seen it come into being because of other groups getting interested in the problem.

11. It was recommended that more attention be paid to the need for dental care. As a result of this study, plus others that were being conducted at the same time, an overall study was made of dental needs in the community. This was a most creative kind of report. It has been implemented by United Community Services, and dental care for any handicapped person or any aging person is markedly improved in the metropolitan area. Services for indigent are also greatly expanded. We have been able to work in one specific area with the Michigan Crippled Children's Commission, by admitting children to Children's Hospital on a commission order where the youngster needs an excessive amount of dental care. Our dentist has then been assigned to treat that child; the youngsters come in overnight, are given a general anesthetic, and a considerable amount of dental work is done in one operation. This has been a very worthwhile service, and many of our children with marked dental problems are now in good status.
  
12. The final recommendation of the survey was a rather general one and summarized the philosophy of care. There were four sections to it. The first, regarding increased participation by pediatricians, is still not fulfilled. We get good participation from individual pediatricians, and when a given doctor has had good service for one patient, he tends to refer others. However, there is no carryover into the general pediatric division of medical societies. For the most part, parents tell each other when they find a good pediatrician and consequently the parents tend to go to certain doctors in our community, and this has been helpful to us in working with a small group of physicians.

The second one, regarding general health supervision for all ages is improving, but very slowly. This is partly due to the fact that the public health nurses who assume major responsibilities for this find it difficult to service a segment of the population when the massive problems of the indigent, the riot area in Detroit and some of these other dramatic programs take so much of their staff.

The third was for better utilization of professional staff. I think the people who have visited our agency recognize that there is nothing static about the way we use staff. It is a very fluid, always constantly moving program, in which we look at the limited number of people and see how best we can use them. I'm not sure that this is true in other areas. I think that we tend still to see a one-to-one relationship in therapy in many agencies. We have not felt that we were either powerful enough nor well-enough situated with time to move very much in this area. We have stayed out of other people's problems until we got some of our own solved.

The discussion of the failure of teenagers and adults to develop adequate psycho-social maturity and their best economic potential is one of which we are all well aware. This is one of the areas in which Executive Task Force Committee is working most intensively in order to develop some pilot projects in terms of in-living for our teenagers to give them some experiences in living away from home. We also are appreciative of the counseling which has been available to some of our teenagers through other agencies; and, of course, we at UCP continue a very active counseling program. As our agencies grow older, we find an increasing age of the patients we are seeing. This has enabled us to change the focus of some of the things we are doing and make it more available to teenagers and young adults as we gain more expertise in working with them.



OVERVIEW: A STATE PROFESSIONAL ADVISORY AND EVALUATION BOARD

Presented by  
Jasper Harvey, Ph.D., Chairman  
Medical-Professional Advisory and Evaluation Board  
United Cerebral Palsy of Alabama, Inc.

Purpose of Board. The Medical-Professional Advisory and Evaluation Board functions in an advisory capacity and submits recommendations to the State Board of Directors on all matters pertaining to the cerebral palsied.

Responsibilities and Duties of the State Board.

1. To assist local Affiliates in securing Medical and Professional representation on their Medical-Professional Advisory and Evaluation Boards.
2. To assist the State Program Service Committee in its efforts to assess the needs for programs at a State level.
3. To carry on a Program of Education among Physicians and Para-Medical groups in the State regarding the problems of the Cerebral Palsied and the unmet needs.
4. To maintain effective liaison with the Alabama Medical Society and the Medical School of the University of Alabama.
5. To maintain effective liaison with the State Department of Education in the field of Special Education for handicapped children.
6. To advise the State United Cerebral Palsy Board of Directors on any matters of professional importance related to the Cerebral Palsied.

In addition to the above noted responsibilities and duties, at the initial organizational meeting of this Board, November 4, 1961, it was stressed that all matters coming before this Board are (a) confidential, (b) this is a Service Board, (c) this Board is available to any discipline that needs help and requests its services, and (d) its purpose is to render unbiased opinions which will help to upgrade all areas concerned with cerebral palsy and to promote ethical processes and procedures.

Membership and Term of Office. Membership of the Board consists of medical, education, administration, and para-medical areas. Specifically, under medical there is an orthopedist, an orthodontist, pediatric neurologist, child psychiatrist, internist, physiatrist, and pediatrician. Education is represented by the Chief Consultant, Program for Exceptional Children and Youth of the State Department of Education, the State Supervisor of Crippled Childrens Service of the State Department of Education, the State Director of the Division of Rehabilitation and Crippled Children of the State Department of Education, the Chairman of the Department of Special Education at the University of Alabama, and the Supervisor of Speech Pathology of the Department of Otolaryngology, Medical College of Alabama. Administration is represented by the Vice-President for Birmingham Affairs of the University of



Alabama in Birmingham and the Medical Center, and the Director of the Division of Community Services of the Alabama Department of Mental Health. Para-medical areas are represented by the Director of the Bureau of Informational Service of the Department of Pensions and Security, the Director of Nursing Service of State Crippled Childrens Service, the Director of Physical Therapy at the University Hospital, an occupational therapist, the Director of Social Service at the University of Alabama Hospital and Clinics and Chief Medical Social Worker of Crippled Childrens Service.

At the second meeting of the Board, February 24, 1962, Dr. Jasper Harvey was appointed to chair a committee to be known as the Internal Government Committee. That Committee submitted the following report at the June 16, 1962 meeting and it was approved after considerable discussion.

1. **SELECTION AND ROTATION OF BOARD MEMBERS.** Selection is to be made by the existing board. Appointment should be made considering three criteria: (1) professional adequacy; (2) desirability; (3) interest and willingness to serve. Rotation of board membership is to begin at the termination of an initial three-year term. Such rotation is to begin at the time of the annual meeting of the State Board of Directors in 1965, with one-third of the membership to be appointed for one year, one-third to be appointed for two-years and the final one-third to be appointed for three-years. Replacement is to be made only if a replacement in speciality is possible.
2. **ATTENDANCE.** Fifty percent attendance is required. After three consecutive absences which are unexcused, a member may be dropped; however, notification of absence from a meeting because of professional commitments may be considered an excused absence. Attendance is to be noted as (1) Present; (2) Excused, Unable to Attend; or (3) Absent, Unexcused.
3. **ATTENDANCE OF MEETINGS BY GUESTS.** Local Affiliate Medical Staff and Advisory Board Members may attend ex-officio so that there may be an interchange of ideas and problems. Guests other than these may attend on the invitation of the Chairman.
4. **FREQUENCY OF BOARD MEETINGS.** Meetings are to be held quarterly. A special meeting may be held at the discretion of the Chairman; however, fifty percent of the Board must be in attendance for business to be transacted.
5. **CHAIRMAN.** The Chairman and/or Co-Chairman are to serve three-year terms. The Chairman or Chairmen are to be selected by the members of the Board. The Chairman is to appoint sub-chairman for any area (or occasion) deemed necessary.
6. **TREATMENT OF REQUESTS FROM INDIVIDUALS.** All problems and/or requests from individuals shall be handled by the Chairman or by his referral to an appropriately designated sub/vice-chairman. If the problem or request be of major import, a special meeting should be called. All matters of policy are to be referred to the general Board.

7. **ADDITIONAL REPRESENTATION ON BOARD.** IT is recommended that three additional representatives be added at this time. These are to be in the areas of (1) anaesthesiology; (2) public health and (3) administration.
8. **SECRETARY.** IT is recommended that the Executive Secretary (National Field Representative) be Secretary to the Board.

As noted above the membership as of this date was described. The Internal Government Committee outlined the membership for the State Medical Professional Advisory and Evaluation Board as follows:

**A. Medical**

- |                                  |                      |
|----------------------------------|----------------------|
| 1. Pediatrics                    | 5. Internal Medicine |
| 2. Orthopedics                   | 6. General Practice  |
| 3. Neurosurgery and/or Neurology | 7. Otolaryngology    |
| 4. Physical Medicine             | 8. Psychiatry        |
| a. Physical Therapy              | 9. Anaesthesiology   |
| b. Occupational Therapy          | 10. Dental Surgery   |
| c. Corrective Therapy            | 11. Public Health    |

**B. Education**

- |                      |  |
|----------------------|--|
| 1. Psychology        | 3. Speech and Hearing Pathology and/or   |
| 2. Special Education | Audiology                                |
|                      | 4. Vocational Rehabilitation             |
|                      | 5. Rehabilitation of Children and Adults |

**C. Welfare**

- |                              |                          |
|------------------------------|--------------------------|
| 1. Social Worker             |                          |
| a. Psychiatric Social Worker | c. General Social Worker |
| b. Medical Social Worker     | d. Nursing Service       |
| 2. Administration            |                          |
| a. Hospital Administrator    | c. University of Alabama |
| b. Agency Director or        | Medical Center           |
| Administrator                |                          |

Functions of the Board. In order to convey the various kinds of services and functions which this board has fulfilled in its six years of operation, those services and functions are listed:

1. Recommended a scholarship program to provide funds for special education teachers for the summer session, 1962.
2. Evaluation of Childrens Center of Montgomery. Specific recommendations were made concerning that program.

3. Established a processing procedure for cerebral palsy patients in unaffiliated areas.
4. Heard agency reports, i.e., Mobile Rotary Rehabilitation Center, Elks Memorial Center, Lee McBride White School, and Pine View Manor. Each of these is an agency which in some way is concerned with cerebral palsy.
5. Heard reports and requests from local medical-professional advisory committees.
6. Case Registry Committee report.
7. Program Service Advisory Committee sub-committee appointed from Board.
8. Preparation of a directory of services for the cerebral palsied in Alabama.
9. Discussion of proposed State legislation.
10. Setting up of a UCP of Alabama film library to be housed at the University of Alabama and to be made available for all affiliates or other interested groups.
11. Planning for a symposium on cerebral palsy.
12. Reports from State and University Special Education.
13. Discussion concerning a new affiliate which was formed in Huntsville and the formation of that affiliate's medical-professional advisory board. From that discussion the purpose and function of an affiliate medical-professional advisory board was developed. Those data are included in Appendix I of this report.
14. Report on symposium which was held in October, 1963.
15. Proposal of new members.
16. Bobath Report.
17. Discussion of education for a cerebral palsied youth at the secondary level.
18. Custodial care for the cerebral palsied.
19. Report of possible medical centers for local affiliates in Alabama. (A comprehensive study, county by county, was made by the Board to determine the medical centers, trade areas, vocational services, rehabilitation services, and possible boundaries for future affiliates. A map showing those boundaries was prepared by the Board. It was recommended by the Board that boundaries as they appeared on that map seemed to be the most functional from the standpoint of available services and that they should compose boundaries future affiliates. A total of seven areas were plotted.)

20. Transportation for a specific child.
21. Special education teacher traineeships, summer, 1965.
22. Report on State Special Education Program.
23. Needs of the cerebral palsied in Alabama.
24. Revision of Directory of Services for the Cerebral Palsied.
25. Discussion of possible new affiliates.
26. Social workers scholarship.
27. Physical therapists scholarship.
28. Day care centers.
29. Mental Retardation Center plans. (This was a discussion of the University of Alabama's Center for Developmental and Learning Disorders which is being built within the Medical Complex in Birmingham.)
30. Need for comprehensive cerebral palsy center for the State.
31. 1966 budget for UCP of Alabama.
32. Preparation of scholarship application forms for United Cerebral Palsy of Alabama.
33. Report of Study for Spastic Aid of Alabama (UCP of Birmingham) by United Cerebral Palsy Associations, Inc., 1966.
34. Election of new members and election of a chairman.
35. Approval for physical therapy scholarships.
36. Teacher training project at the University of Alabama in the area of the crippled.
37. Approval of special education scholarships.
38. Approval of social workers scholarships.
39. Approval of physical therapy scholarships.
40. Discussion of Childrens Bureau meeting and representation from this Board.
41. Orientation of new Board members.
42. Report of Research Grant to the University of Alabama Medical Center.



43. Report by Mobile affiliate of research project on "Neurological Developmental Program."
44. Joint Meeting of Medical-Professional Advisory and Evaluation Board with Board of Directors, UCP of Alabama.
45. Develop a proposed program for UCP of Alabama for 1967-68.
46. Discussion of Cerebral Palsy Treatment Center.
47. Report of long term study of treatment methods in cerebral palsy.
48. Approval of Board and recommendation to State Board of Directors to proceed with capital fund drives to finance a State cerebral palsy facility to be located within the Medical Center of the University of Alabama.
49. Report of "Developmental Therapy Program" with demonstrations and discussions.
50. Discussion of Mental Health-Mental Retardation Centers.
51. Education report.
52. Hackberry Program report, University of Alabama summer program for the crippled.
53. Report on dental problems of the cerebral palsied.
54. Atlanta Hearings.
55. American Academy for Cerebral Palsy Meeting, San Francisco Hilton, December 10-13, 1967.

## APPENDIX I

### PURPOSE AND FUNCTION OF AN AFFILIATE MEDICAL-PROFESSIONAL ADVISORY BOARD

After an excellent discussion on the purpose and function of a Local Medical-Professional Advisory and Evaluation Board it was agreed that the following conclusions be made available to local Affiliates:

1. The President of the Affiliate should meet with the Chairman of the Medical-Professional Advisory Board at least once a month to discuss the local program, existing cases, problems, etc. Where there is an Executive Director it is the responsibility of the Executive Director to call the meetings of the above mentioned people. The Executive Director with the help of the President and Chairman of the Medical-Professional Advisory Board plans the "Agenda" for Board Meetings.
2. A prepared typewritten agenda should be well prepared and before all Board members at the Board meetings. It was suggested that when it is possible the Agenda should be distributed to Board members prior to Board meetings. If this is not possible, it was suggested that the notice of the meeting should indicate topics to be discussed.
3. There should be a set schedule of meetings at least three meetings a year. Set dates, list them in the minutes. Notices should be sent two weeks in advance with a follow-up five days prior to the meeting.
4. Minutes should be mimeographed and supplied to each member.
5. Appointments to the Medical-Professional Advisory and Evaluation Board should be approved by the Affiliate Board of Directors before the prospect is invited to serve.
6. A Medical-Professional Board must be "active" to be "effective." Attendance at meetings is essential for success. If a Board member misses three consecutive meetings without an excused absence the member should be replaced.
7. The Medical-Professional Advisory Board should investigate action if at any time the program of services bog down. In other words, if the President of the Affiliate or the Board of Directors fail to request help from the Board--this does not mean that the Advisory Board should not function. Quite to the contrary, the Board should evaluate the program of services at least once a year and should submit its recommendations to the Board of Directors.
8. The chairman of the Medical-Professional Advisory Board should represent the Board on the Board of Directors of the Affiliate.

## PROFESSIONAL SERVICES PROGRAM COMMITTEE

Summary of Presentations of  
 Oscar O. Selke, M.D., UCP of Texas  
 Donald Rathbun, M.D., UCP of El Paso  
 Frazer Banks, UCP of Pensacola, Florida

- I. The Medical-Professional Advisory Board of UCP of Texas is an action board. (Ed. Therefore, is an example of how a Professional Services Program Committee recommended in IHF Plan might function.)

Twenty years ago orthopedics was its main activity, but the UCP of Texas has since developed wider care to cover the wide range of disabilities occurring in individuals with cerebral palsy. In summary, the state Advisory Board brought about these changes:

- A. Started by supplying speakers about C.P. at Annual Meetings of the Texas Medical Association. These developed into seminars, such as "Discriminating the Potentiality of Dysfunctioning Children" (1968) by Dr. Eric Denhoff.
- B. When a survey showed the need for dental care, UCP of Texas put "seed Money" in to start a Dental Workshop at Baylor University for Care of the Handicapped. Another developed in Houston at University of Texas where materials will now be incorporated in dental school curriculum.
- C. Public Health Nursing seminars were organized.
- D. Dr. Helfer of San Antonio is developing an evaluation profile from neurological workups in such a way that they can be computerized. Dr. Rathbun of El Paso is developing an extension of this in the area of Minimal Brain Dysfunction. The data is being put into the Department of Mental Health computers for statewide analysis. Eventually UCP of Texas hopes to develop a Profile of Information on Cerebral Palsy which may serve as a guide for evaluation in all areas. [Ed. For other evaluation studies, consult National Institute for Neurological Disorders and Blindness; also Academy for Cerebral Palsy.]

II. The Use of Professional Consultants - National, State and Local

Like many other affiliates, UCP of Pensacola was plagued with budget limitations, community apathy and understaffed programs. Professional consultants, generously supplied by the UCP state and national associations, pointed out recognized needs; but, unfortunately, "took the next plane out." This left implementation of their recommendations to the Board Members. After these recommendations had been made repeatedly by UCPA Consultants, positive action was taken in 1967 by UCP of Pensacola by finding a local educational consultant and forming a local professional advisory committee.

## PROFESSIONAL SERVICES PROGRAM COMMITTEES AND THEIR ROLE IN PROGRAMMING AT THE LOCAL LEVEL

Draft - 1966  
UCPA Services Advisory Committee

### INTRODUCTION

As UCP has matured there has been a gradual change in the concept and emphasis of programming and the role professional advisory boards should play.

In the beginning years the emphasis in programming was on medical programs aimed at physical restoration. Hence affiliates were urged to have medical advisory boards. It soon became apparent however that the medical aspect of programming represented but one area of need and that in planning total management specialists from other areas were needed, e.g., special education, psychology, recreation, social case work, long-term care, etc. It was therefore recommended to affiliates that the advisory group be a combined medical and professional group.

In theory plans for programming were to be brought to the advisory group for study and recommendation. The recommendations were then presented to the boards of directors for action and implementation, usually through the Program Services Committee. In practice, this did not always work. The advisory groups were too far removed from the program activities of the affiliate to make pertinent suggestions and they were too busy to attend the in-service training programs of the national and state Program Services Committees which were attempting to keep both lay and professional workers current on new program developments across the country.

To try to remedy these situations, the national Service Program Committee recommended that the PROFESSIONAL SERVICES PROGRAM COMMITTEE become an operating committee at the state and local level, combining the functions and responsibilities of the Medical and Professional Advisory Board and the Program Services Committee. It was further recommended that some experienced and knowledgeable lay persons be added and that official liaison be established between the committee and medical societies, as well as health and welfare planning councils.

### RECOMMENDED STRUCTURE

The Professional Services Program Committee be an operating or standing committee with representation on the Board of Directors.

### MEMBERSHIP

Professional Services Program Committees should have:

1. Representatives of the various professional disciplines from areas in which the affiliate is programming;
2. Representatives from the major programming areas, namely, medicine, dentistry, education, recreation, vocational service, social case work, psychology, nursing, etc.



3. Representatives from other agencies in the community serving the cerebral palsied;
4. Official liaison with the local medical society;
5. Official liaison with the local health or welfare planning council;
6. Some lay persons knowledgeable and experienced in service program matters.

By double and triple "hatting" individuals, committee size can be kept within manageable limits. If possible, individuals should be chosen from decision making positions, e.g., director of public school special education for the special educator or director of the group work program from the city recreation department for the recreation representative. However, "status" names and positions should only be used if these individuals will actively participate in the work of the board. Some provision should be made for rotation, e.g., three-year terms with one-third of the members reappointed or replaced each year.

#### RECOMMENDED FUNCTIONS

All measures relating to program planning, development and implementation should be referred to the Professional Services Program Committee before action is taken by the board of directors.

All contractual relations for service should be reviewed by the Professional Services Program Committee and their recommendations carefully considered before action is taken.

The basic programming policies of the affiliate should be determined by the Professional Services Program Committee. These would, of course, reflect the program policy of national UCPA, e.g., every effort should be made to utilize existing services in the community before a new service is initiated, that UCP has a moral responsibility to see that services are available for CPs of all ages and all degrees of disability.

#### TYPES OF RESPONSIBILITIES

Experience has shown that busy professional people will participate enthusiastically on advisory boards when they are given responsibilities that are challenging to them and in keeping with their professional skills. Conversely, they lose interest quickly if they feel that they are being used as "yes" men or for status purposes only. Suggested areas of responsibility are:

1. Determination of program policies -- in terms of community needs and resources, which areas of service should receive UCP dollars, which programs should the affiliate attempt to shift to other community agencies, where should the programming emphasis be this year -- five years from now, etc.
2. Initiate program planning. No new program should be added without prior study and recommendation by the Professional Services Program Committee.
3. Regular re-evaluation of on-going programs -- this should point up which areas need strengthening, modification, shifted to other agencies, dropped in order to serve better.
4. Review of the program budget in the light of needs and numbers of persons being served.
5. Study specific program problems referred by the Board of Directors.

It would be pointed out that the deliberations and decisions of the advisory board should go as recommendations to the board of directors of the affiliate. The final decision in programming as in all other affiliate matters should rest with the group responsible to the community, namely, the Board of Directors.

#### SUGGESTED AGENDA FOR NEW BOARDS

1. September: Opening meeting  
Orientation in UCP Philosophy and Criteria for Programming.  
Affiliate's history of program and present on-going program.  
Other services for CPs available in the community.
2. November: Goal setting, immediate and long-range  
Decision on how to proceed through a  
National Staff Evaluation  
Local Study Consultant  
Self evaluation by study group  
Assignment of responsibilities.  
Problems of immediate concern.
3. February:  
Reports of the sub-committees  
Drawing up tentative goals  
Problems of immediate concern.
4. April:  
Review of program budget for next year  
Problems of immediate concern.

#### RATIONALE BEHIND THE RECOMMENDATIONS

Programming is a complicated process involving:

- Knowledge of total management needs
- Knowledge of research and experience of others in the particular area under consideration
- Knowledge of community resources
- Familiarity with techniques for assessing need in a particular situation
- Ability to estimate costs for a proposed service
- Ability to estimate space needs and optimal location
- Balancing the cost, space and staff needs against the number of individuals to be served and the on-going program
- Evaluating the effectiveness of the program.

Boards of Directors must be concerned with many other aspects of affiliate operation in addition to programming; e.g., financing, supervision of administration, interpretation of the community. In most instances, and especially if the affiliate operation is sizeable, they do not have time or the background necessary to meet complicated programming problems.

The multi-discipline approach to programming is absolutely essential to provide for the total life-long needs of cerebral palsied individuals.

The inter-agency representation on the PROFESSIONAL SERVICES PROGRAM COMMITTEE not only makes possible inter-agency cooperation and coordination of service thus avoiding duplication of effort, but also helps achieve a better balance in community programming in terms of actual need.

## CONTINUING EDUCATION FOR STAFF

Presented by  
Jay Schleichkorn, Executive Director  
UCP of New York State

"Continuing Education" is relevant to all of the work we must do in United Cerebral Palsy. Consideration must be given to the ever-increasing role that "continuing education" for professional personnel and volunteers will play in future programming of our association. In simple terms - continuing education is the opportunity for an individual to obtain the tools and information which will keep him abreast of the many everyday challenges that we face as programs are being developed. Continuing education may be short-term training programs, graduate work, special conferences, assemblies, seminars, classes, or gab sessions. Mainly, it is any opportunity that allows for the development of continued thought on how to do a better job. To everyone working for the cerebral palsied doing a better job should be our prime concern. While it is very important to improve skills in every profession, it has become apparent in United Cerebral Palsy that the director who is given the responsibility to administer an association must be a "jack of all trades."

Dr. Donald P. Conwell, Medical Director of the Bureau of Disease Prevention, U.S. Public Health Service, in the June issue of the "Labor Relation Report": "Once health professionals had whatever degree they were seeking, it was thought that they had a major portion of the knowledge concerning that field. This, too, has fallen before the electronic age. When you consider that there are about 2,000 different health journals published monthly, then the enormity of the mass of knowledge is put into perspective. It would be futile to attempt to absorb all those words to say nothing of ideas."

Dr. Conwell points out that no one is expected to have absorbed all the information in his own specialty area. He stated "Even so, there is a certain amount of new information that every professional must absorb, either in a concentrated or an osmotic atmosphere. We have chosen to call this continuing education."

Rome G. Betts, Chairman of the Committee on Continuing Education of the National Health Council, and Executive Director of the American Heart Association, recently wrote: "Technical and scientific advances, social and economic progress, national and international developments combine to make continuing education essential throughout life. Swift changes in community health and related fields make it increasingly clear that the body of knowledge in use by any health professional at any time is constantly shifting. Knowledge acquired in basic formal education may have only a slight relationship to that needed in today's society."

It becomes even more apparent to those of us in United Cerebral Palsy that there is a definite need for a structured program of continuing education. If you review their background, you will find that executive directors often are any one of the following: a physical therapist, psychologist, social worker, teacher, nurse, attorney, vocational counselor - almost any discipline related to the rehabilitation field. A few directors and administrators have even come from the clergy, business administration and the military service. We have many dedicated people from many different fields, but, because they come from such a varied background, it is even more important that the role of continuing education be stressed.



Once a person is employed as an executive director at this exciting work, he or she is immediately thrown into a situation from which only a Houdini could possibly escape. Because there are so many aspects to the position, it behooves any local policy making group, or the next higher echelon, to recognize how important continuing education is to support their staff and volunteers.

Continuing education is not limited just to the voluntary health field. At Harvard Graduate School of Business Administration just about every class is made up of a president, a chairman, or a vice president of a well-known company who wish not only to extend individual skills but also to add to their understanding of factors in today's society that effect the general problems of the industry as a whole. Why can't this same concept apply to the executive directors, clinic administrators, and other professional personnel in United Cerebral Palsy? Our personnel might gain techniques to cope more effectively with everyday problems ---- to increase their abilities ---- reexamine their own role in the total program picture. Of great importance - continuing education would allow our directors an opportunity to be re-freshed and stimulated through the gaining of additional knowledge.

We, in United Cerebral Palsy, have done very little in the way of offering continuing education to the staff of our affiliates. In contrast, look at the type of programs offered by some of the other national agencies. For example since 1909 more than 1,100 members of the National Conference of Tuberculosis Workers have an opportunity to exchange ideas, discuss mutual problems, and to bring their needs and viewpoints to the attention of the National Tuberculosis Association. Since 1923, the National Tuberculosis Association has helped to support the Conference through an annual budget appropriation.

Every year, staff of National Society for Crippled Children and Adults (Easter Seal Society) gather in Chicago for a week of intensive inservice training. They also become acquainted with the aims, changing policies of the organization and methods for interpreting these at the local level.

National Foundation has regional inservice training programs for continuing education; the American Cancer Society, and the American Heart Association have also indicated their interest and concern for continuing education through its heavy support of special courses for executive directors and administrators offered by the National Health Council. In contrast, United Cerebral Palsy had only 6 staff people attend 5 different National Health Council Courses in 1967. Of the 6, three were sent by their affiliates; one received a public health service stipend; another had his expenses shared by a public health stipend and affiliate support, and one paid her own way. Seven other staff people applied for courses, but, for such reasons as no funds available, stipends being insufficient, agency had no funds, they withdrew and did not attend any training programs.

While our association has supported the principle functions of the National Health Council and is listed as an active member, no stipends are made available. At this point, I would like to commend the National office for, at least, distributing the material about the National Health Council courses and playing a role in referring personnel to the Selection Committee. I must also mention that our National Association, in a way, offers some continuing education through the Regional Conferences and special staff fund-raising clinics.



These special programs, however, do not take the place of continuing education or inservice training. There is need for wider representation of staff and for both formal and informal approaches to some of the problems encountered by our executive and clinic directors. I am aware that on many occasions new directors have received the opportunity to visit with the personnel at the National office in order to become better acquainted with some of the policies and overall picture of United Cerebral Palsy. However, I respectfully submit that such a visit in isolation should, in no way, be a substitute for the concept of inservice training or continuing education where sharing of information with those who are doing similar work is so important. Just being able to talk about the same type of community boards, agencies and so forth, is of great value. Perhaps the visiting individual is at a disadvantage, since only two people in the National office ever worked with a local affiliate, and one of these was a president. While I have spoken mainly of directors of affiliates - I, in no way, mean to dismiss the role of continuing education and inservice training for field men, national staff, or state directors. Just as we seem to be willing to offer all types of programs for the volunteer, I would hasten to promote this overall concept of training for anyone working within United Cerebral Palsy.

At an Institute I attended at Princeton University, I made the statement: "We, in United Cerebral Palsy, are running 'A big business.' We are raising more than 11 million dollars and handling all types of community funds, governmental grants, and other agency monies. Every opportunity must be given to those responsible for the management of our association to better their knowledge of business administration, accounting, communication, leadership and so forth."

In conclusion - How can we offer continuing education to our personnel? Some of the suggestions passed on to me by colleagues in the field include the following:

1. Affiliates' Board of Directors should recognize the value of training their staff members.
2. Our National Association could bring about a better understanding and direction for local affiliates by demonstrating their concern for staff training. This could be done through sponsoring of continuing education in partnership with whatever mechanisms are now available, or through some type of stipends.
3. The concept of funds being budgeted at various levels for professional training should be considered.
4. Some type of an evaluation procedure to determine the value of inservice training should be developed.
5. The experiences of other national health agencies should be looked into and reviewed as to how they offer training to their staff.
6. Where funding may be a problem financial support from federal and state agencies should be investigated.
7. Should the value of continuing education be recognized as policy, a joint volunteer and staff committee should be given the responsibility for developing a program for all of United Cerebral Palsy.
8. The dissemination of information about continuing education courses should be the responsibility of the National office, together with either an endorsement or some type of recommendation to guide the local Board of Directors.

In summary, perhaps these 8 recommendations are not all inclusive at this time. If we are to plan constructively, I strongly urge that every consideration be given to maintaining and developing some procedure through which any staff member will be able to continue his education. We are facing a time for decision. Either an affiliate remains at a plateau when the administration is not given the "tools of the trade", or United Cerebral Palsy moves ahead with progress in all areas due in part to continuing education that will excite the imagination of its personnel.

ROLE OF UNITED CEREBRAL PALSY ASSOCIATIONS IN NEW YORK STATE  
AND STAFF TRAINING AT STATE SCHOOLS FOR THE MENTALLY RETARDED

Presented by

Robert C. Bartlett, Director of Program Services  
UCP of New York State, New York

In the text "Teaching the Mentally Retarded" Bensberg states: "All individuals, regardless of age or intelligence, developed best when they received proper physical care, training and stimulation in an atmosphere which meets their emotional needs." The individual who will provide this stimulation may be best described in the book, "The Child Who Never Grew" by Pearl S. Buck when she said, "The most important person in an institution, so far as the child is concerned, and therefore so far as the parent is concerned, is not the Executive and not the man or woman in the office, not even the doctor and the psychologist and the teacher, but the attendant, the person who has direct care of the child." This particular philosophy has come under a great deal of criticism by some professionals, due to what they say will be a lack of quality control and adequate programming for the mentally retarded. Considering the fact that most institutions have an extremely large census, the role of the professional individual will not always be only one of direct care, but also that of a consultant offering continued guidance and direction to the supportive personnel within the institution. By utilizing supportive personnel, the service available to many residents of the institution will be extended.

The UCP of New York State believes it can be of assistance by providing inservice training to augment the role of the aide and attendant. In New York State, all institution attendants have previously had initial pre-employment training, but for some it has been as many as 5 to 10 years ago.

The general purposes of UCP inservice training presentations are (1) to strengthen inter-staff relationships between the rehabilitation personnel and the attendant, (2) to make the attendant more aware of the problems he must cope with and the methods he could use in the ward situation to care for the individual with mental retardation. In our initial planning, we felt that one of the prerequisites should be that a member of the professional staff of the institution be involved in the presentation of the program in order to insure a follow-through on the information which was being presented. However, we found after a number of experiences within the institutional setting, that the experience of the existing staff in working with the multi-handicapped was limited, and the role they could play within an inservice training program had to be curtailed.

To meet the goals of training for the attendant, we followed the following general curriculum:

- Unit I:
- A. Definition of Mental Retardation
  - B. Characteristics of Mental Retardation
  - C. Causes of Mental Retardation
  - D. The Inter-Relationship of Conditions Associated with Mental Retardation

Unit II: A. Growth & Development of the normal child and its implication for the retarded child.

1. Guide of Developmental Milestones
2. Reflex patterns
3. Basic reinforcement techniques

Unit III: A. Day Care (Nursing Techniques)

1. Early feeding techniques
  - a. Nipples
  - b. Positioning
2. Dressing and adaptive clothing
3. Advanced feeding with special equipment
4. Development of basic toilet habits
5. Contracture

Unit IV: A. Adaptive Equipment

1. For sitting:
  - a. special chairs
  - b. wheelchair inserts
2. For standing:
  - a. standing tables
3. For movement:
  - a. creepers
  - b. walkers
  - c. crutches

Unit V: A. Recreational Activities and Constructive Use of Leisure Time.

In order to achieve projected goals, it is most important that our state association staff follow up and confer with the professional staff of the institution who are supervising the implementation of the program for the multi-handicapped. If not, the professional staff, who many times have limited experience with the techniques presented will be unable to cope with the questions that arise on the wards, and the program will fail.

We have been pleased with the improved care offered to patients in the facilities where these programs have been presented, as well as the new "areas of service" which appear to have been stimulated by our efforts. The cooperation and reception on the part of the staff of these facilities has been wonderful.

We also feel that the relationship between United Cerebral Palsy as a major referring agency, and the schools for the mentally retarded has been improved since we demonstrated our continued interest in the multi-handicapped child, even after placement, and that as an association, we do not just "dump" the children with whom we are unable to achieve results in the community.



PROGRAM TRAINING OF SUB-PROFESSIONAL VOLUNTEERS  
FOR A PRE-SCHOOL CENTER

Presented by

Jean M. Shirreffs, Program Director  
UCP of Union County, New Jersey

The shortage of qualified trained professionals is a general problem in the administration of special education programs. It is especially grave in pre-school programs for children with cerebral palsy because (1) this is one of the smallest groups of handicapped individuals and as such has not received adequate attention from teacher training institutions and (2) this population is often characterized by multiple handicaps including mental retardation and difficult to detect perceptual deficits which complicate educational diagnoses and prescriptive teaching. Thus a development of new approaches to training volunteers which would allow them to assume defined instructional roles in the education of young children with cerebral palsy is deemed to offer a provocative alternative to the shortage of trained professionals.

A project undertaken at the United Cerebral Palsy Center of Union County in Cranford, New Jersey investigated the feasibility of instructing sub-professional volunteers to work independently with pre-school children in a tutorial capacity by using a mixed media self-instruction process.

During a six-month pilot period ten activities derived and adapted from the work of Barsch and Kephart were selected. Ten sets of programmed materials were created using a model proposed in Lange's "Programmed Instruction." Each set consisted of (1) a written instruction sheet which clearly delineated the sequence of the activity broken down into small steps, and (2) an accompanying 8 mm. demonstration film on a continuous loop which followed and thus reinforced the steps of the written instruction sheet.

Each set of programmed materials as developed was deemed effective only if it allowed at least 90 per cent of the volunteers to master the content of the programmed set and demonstrate their learning by 100 per cent accuracy of performance within a learning period of thirty minutes.

Ten volunteers participated in the initial field testing of these materials. These women were part of the center's permanent volunteer group. To test the effectiveness of the materials for another population, a second group of ten teenagers was selected and tested in the manner indicated.

Results demonstrated that no learner exceeded the thirty minute criterion time on any program. This project demonstrated that programmed training materials could be developed to train sub-professional volunteers. For a more detailed account of this procedure see "Programmed Training of Sub-Professionals to Supplement Instruction in Pre-School Programs for Children with Cerebral Palsy", by James Q. Affleck, Shelia Lowenbraum and Jean M. Shirreffs in The Cerebral Palsy Journal, July-August, 1967.

## SPECIAL STATE LEGISLATION

Presented by

Walter H. Richter, Director, Southwest Region  
Office of Economic Opportunity, Austin, Texas

In my assignment to round up special state legislation for the handicapped, I shall limit myself to certain topics which I believe are of special interest to you. In addition, I shall discuss the manner in which the Office of Economic Opportunity makes provision for disadvantaged persons, many of whom are handicapped or mentally retarded.

- I. "PKU" is an inherited metabolic disorder due to the lack of an enzyme needed to break down phenylalanine, an amino acid found in proteins. When the enzyme is missing the partially metabolized products of phenylalanine build up in the blood. Brain damage and mental retardation result. When the defect is discovered early, the infant can be placed on a special diet low in phenylalanine and retardation prevented.

In recent years, various simple screening tests of the urine and blood have been developed for the identification of persons with "PKU". Usually, newborn infants are subjected to a test before they are discharged from the hospital.

The blood test must not, however, be performed until after the infant has been on milk feedings for 24 hours. A second test is usually recommended at 4 to 6 weeks of age to detect borderline or low levels of phenylalanine in the first few weeks of an infant's life. It will also confirm a positive initial test.

The frequency of "PKU" among newborn infants is reported to be 1 per 8,000 to 20,000 births.

With the exception of six or seven states, each state by law makes some provision for the testing of newborn infants for "PKU". In the majority of these states, the testing is made mandatory. However, in every state the law provides that the test is not required to be given or administered to a child whose parents object on the ground that it conflicts with their religious beliefs.

## II. Elimination of Architectural Barriers

Under sponsorship of the President's Committee on Employment of the Handicapped and the National Society for Crippled Children and Adults, the American Standards Association developed a set of standard specifications entitled, "Making Buildings and Facilities Accessible to and Usable by the Physically Handicapped."

There are thousands of public buildings in the United States that are not truly public. They are not open to all who might wish to enter. They are not open to the seriously handicapped. There are no barriers that say "Handicapped Keep Out." But they do have built-in barriers which prevent

persons with physical disabilities from making full use of them, such as flights of steps to enter the building, rest rooms with facilities not suitable for wheelchairs and telephone booths too narrow for a wheelchair to enter or telephones with no amplifying device for the deaf, hazardous doorways, and so on.

If the handicapped cannot enter public buildings, they cannot hope to hold jobs there. Nor can they hope to conduct their affairs there.

Approximately 34 states have passed state laws to eliminate architectural barriers in public buildings and make them accessible and functional to the handicapped.

In April, 1966, President Johnson announced the establishment of the National Commission on Architectural Barriers for Rehabilitation of the Handicapped. The Commission was authorized by Congress as part of the Vocational Rehabilitation Amendments of 1965.

The Commission will determine how and to what extent architectural barriers impede access to or use of facilities in buildings used by the handicapped. It will determine what is being done to eliminate such barriers from existing buildings, and to prevent barriers being incorporated into buildings constructed in the future.

The general public -- you and you and you -- can let your wishes be known. You can tell responsible officials that you want these specifications to be made part of all public buildings. You can let them know you are in favor of any means and any programs which result in broader equality for the handicapped of your community.

### III. Legislation Enacted in the States on "Battered Child"

The Children's Bureau, charged with the responsibility since 1912 of investigating and reporting upon all matters pertaining to the welfare of children and child life among all classes of people, has in recent years, focused special attention on children who have been physically abused by other accidental means by their own families. Physicians, social workers and others interested in the welfare of children are in a position to recognize many childhood injuries sustained through such physical abuse. Evidence of such abuse began to pour into the Children's Bureau.

In 1962 the Children's Bureau called together a group of consultants to consider what might be done. The members of the group agreed that these children were in need of protection by the community, but first they had to be found and identified before they could be protected from further harm. The group therefore recommended the passage of state laws which would require physicians to report these cases to community authorities as a first step in the protective process. As an outgrowth of the group's recommendation, The Children's Bureau, in 1963, published "The Abused Child - Principles and Suggested Language for Legislation on Reporting of the Physically Abused Child," to serve as guidelines for the states.

State legislatures began to pass child abuse reporting laws during the 1963 legislative sessions, and by 1966, 51 such statutes were in existence, including the District of Columbia. Each state tailored legislation to meet its own circumstances. Therefore, there is considerable variation in the content of these laws.



Although the laws deal mainly with persons who are required to report cases of child abuse, there is nothing in these laws which preclude the voluntary reporting by persons with knowledge of physical abuse of children by other than accidental means.

The majority of the state statutes requires the reporting of child abuse cases upon children under 16 years of age, others under 12, 15 or 18. California, Minnesota, Utah and Wisconsin require the reporting of such injuries upon any child or any incompetent or disabled person.

Persons participating in the making of a report, who are usually physicians, institutions, nurses, social workers or law enforcement officers, or who participate in a judicial proceeding resulting from such report, are immune from any civil or criminal liability that might otherwise be incurred or imposed. Some states provide such immunity if the report is made in good faith.

It is the intent that as a result of such reports, protective social services shall be made available in an effort to prevent further abuses, safeguard and enhance the welfare of such children, and preserve the family life wherever possible.

#### IV. Abolishment of Charitable Immunity

A charitable organization, under common law, could escape liability in any action brought against it by interposing a defense that it was a charitable organization. This was based on the theory that trust funds created for charitable purposes should not be diverted for the purpose of paying damages arising from the torts of servants and agents. Another theory for such immunity from liability for torts was based generally, either expressly, or inferentially, on public policy. A third ground of exemption was based on the theory that, where one accepts the benefits of a public charity, he exempts, by implied contract, the benefactor from liability for the negligence of the servants in administering the charity, at least where the benefactor has used due care in the selection of those servants.

In recent years, however, there is a trend throughout the country to abolish the charitable immunity defense of charitable organizations in tort actions, in some states by court decisions and in others through statutes. It is the law in some states that where a charitable organization has insurance coverage for negligence it is deemed to have waived its immunity from such liability for negligence or any other tort.

It seems it would not be good public policy to relieve charitable organizations from liability for torts or negligence where innocent persons suffer through their fault and in the long run, this will tend to benefit them and the public as well as persons injured. Further, it would be almost contradictory to hold that an institution organized to dispense charity shall be charitable and extend aid to others, but shall not compensate or aid those injured by it in carrying on its activities.

It is because of this trend toward abolishment of the defense of charitable immunity through court decisions and through statute law, that we have during the past several years through our Bulletins and at meetings advised our affiliates to examine their liability policies to assure proper and sufficient coverage. In some instances, it may also be advisable to obtain malpractice coverage.



## V. State Legislation Regulating Solicitation of Funds from the Public

Numerous bills have been introduced in state legislatures on this subject in order to try to protect the public. A great many of these bills, if enacted into law, would have made it virtually impossible to conduct fund-raising campaigns because of severe limitation of the cost of solicitation. No voluntary health agency could possibly have kept within the cost limitation set forth in these bills.

Very fortunately, only a very few of these bills ever became law and the limitations of the cost of solicitation are being seriously considered in court proceedings. Of course, we all agree that, to the best of our ability, we should limit, as far as possible, the cost of soliciting funds from the public.

As a result of the introduction of all of these bills, the National Health Council appointed a committee consisting of the American Heart Association, the American Cancer Society, the National Tuberculosis Association, which is now known as the National Tuberculosis and Respiratory Disease Association, the National Foundation, and United Cerebral Palsy Associations. Harry Lyons, Director of the Legal and Legislative Department, represents UCPA on this committee.

This committee unanimously agreed that there is need for a device to inform and alert voluntary health organizations about proposed, pending and existing regulatory legislation.

This consultant group requested that the National Health Council urge all national voluntary health agencies to participate in this effort on a continuing basis. Since the majority of the regulatory legislative activities takes place on the state and local levels, the success of this effort is dependent on the complete cooperation of all affiliates of these national health agencies to keep the national office informed of such activities within their respective geographic areas.

This consultant group is fully aware of the fact that unless this regulatory legislation is kept within sensible and workable bounds, many health agencies might find themselves unable to carry on the purposes for which they are organized.

## VI. Public Transportation of the Handicapped

Not many months ago, there was added to the President's Cabinet the Office of the Secretary of Transportation.

One of the important items being considered by the Office of the Secretary of Transportation is an analysis of the transportation needs of the handicapped.

Transportation provides access to the community and its activities. To the extent that it is unavailable to any group, that group is denied full participation in the society. The transportation system as we know it today either completely shuts out or unreasonably restricts one particular element in our society -- those whose physical capacities are significantly below the fully-functioning individual. Transportation systems have been designed for those in the positive state of "good health". There is a need to make our planning processes more sophisticated and/or humanly responsive in order to account for

the broad range of physical capacities actually present in the population. There is also a need for a more vivid grasp of the transportation needs of the handicapped.

In the month of November 1967, the Department of Transportation, in seeking an analysis of the transportation needs of the handicapped, invited many organizations to submit proposals to furnish research and study services under a contract with the Department of Transportation. The study is also directed toward aged people who are experiencing difficulty in using present types of public transportation.

It is apparent, therefore, that the Federal Government, through this Department of Transportation, is earnestly seeking a remedy for the public transportation of the handicapped and the aged.

THE USE OF SEED MONEY  
Presented by  
Robert L. Powell, President  
UCP of Wisconsin

I. The pursuit of program activities should not be hampered by artificial rationale or justification. Whether implied or imagined, the threat of..."federal control"..."state control"..."loss of identity"...does prevail. It is the provincialism of an affiliate and of a state association, that allows itself to become intimidated by these purported threats. A realistic recognition and appraisal of existing services, programs and policies swiftly diminishes the restraints of this provincialism.

We shall highlight a few examples of how a state association, UCP of Wisconsin, effected new programs through the use of "seed money". Prior to United Cerebral Palsy involvement, the "examples" were non-existent and came to fruition via our encouragement and commitment.

A. Cerebral Palsy Out-Patient Dental Clinic - Central Wisconsin Colony and Training School.

Several years ago, resulting from meetings and discussions with the Superintendent of the Colony, their Medical Director, their Chief Dentist and the Program Services Committee for U.C.P. of Wisconsin, the need for an identifiable C.P. dental clinic was documented. The goal agreed upon was three-fold:

- 1) To improve dental services and facilities for children committed to and residing at the institution(s).
- 2) To provide out-patient dental services to multiple handicapped children from the communities with appropriate referral.
- 3) To provide training and practical learning experience to practicing dentists from the communities.

In order to achieve these goals, U.C.P. of Wisconsin agreed to:

- 1) Support and fund special training programs for the Chief Dentist and his staff (notable among the several work-experience visits were Dr. Sterlings' trips to the dental program at the University of Indiana and Seattle, Washington, both U.C.P. sponsored facilities).
- 2) To provide grants from the State Association budget (and encourage similar expenditures by the local affiliates) for the purchase of "specialized" equipment.
- 3) To work cooperatively with the professional personnel from the Colony in seeking approval and sanction from the State Dental Association and the State Department of Public Welfare, Division of Institutions. Approval by the latter was extremely important.

If the "seed" money of U.C.P. of Wisconsin was to be effective, then the "Program concept" required not merely approval, but assurance of inclusion in the biennium funding on a permanent basis. It would be grossly presumptuous and an over-simplification, if we pretended that the "project" merely required "discussions and money".

On the contrary, the obvious "problems" (associated with any program endeavors) were accompanied by a subtle, yet extremely sensitive concern expressed by two import-

ant and powerful groups: The State Dental Association and the Marquette University Dental School. Assurances had to be and were given that the C. P. Dental Unit was not usurping the dental curriculum role of the University, nor would the Unit infringe upon the dentist in private practice. Assuagement of all "concerns" for these two groups was vital, in fact tantamount to ultimate approval by the Department of Public Welfare.

Results: The "program" some three years in the making, announced its formal opening in 1966. It is currently an on-going facility at the Colony, completely funded under the institution's biennium operation. The Unit has provided improved and comprehensive dental services to the children in residence. Its unique and portable equipment has allowed for freedom of movement within the wards, enabling it to serve even more children. Perhaps most exciting though, was and is the acceptance by the dental profession throughout the state. At the request of the State Dental Association, two one-day workshops were held at Children's Hospital for practicing dentists in and around the Milwaukee area. Faculty for these workshops came from the Central Colony. Each workshop had maximum participation (45 dentists).

While numerous individual dentists have had field trips and site visits to the Colony, perhaps one of the most impressive sessions was a party of five (from a northern community) who chartered a plane at their own expense and spent a day with the Dental Unit. Resulting from this session and with the cooperation of the local affiliate serving that particular area, a dental unit was established at the community hospital. To date, directly traceable to the Colony concept, are four such community programs with two more in the development stage.

B. Teacher Training - Special Education, University of Wisconsin - Madison.

A complete course description may be obtained from the University. However, a few comments relative to program inception and support would be appropriate.

In many instances children with cerebral palsy were being excluded from public school participation because of a rather simple, yet serious limitation. Quite candidly, the limitation was with the teacher...who, not by design, but because of limited experience felt intimidated when confronted by the C. P. child. While U.C.P. of Wisconsin, via seminars, workshops, institutes, etc., attempted to provide insight and "real experience" situations, it was felt that a specific course offering, introduced into the special education teacher curriculum, would be much more effective and meaningful. Preliminary meetings between University faculty and U.C.P. of Wisconsin program members resulted in the attached program. Significant to the course is the "overview" given the teacher. The attempt to instill a broader concept for teachers and a practical exposure to not only the clinical aspects, but also supportive service functions within the community. Hopefully, a recognition and acceptance by the teacher that his professional responsibility is not confined to the classroom alone, will also be gleaned. In assuming support of this program, U.C.P. of Wisconsin, with local affiliate participation as well, funded the "course" for a one year period with the understanding and agreement that the "course" would become a regular curriculum offering with faculty support being assumed during the second year and thereafter, by the University.

The course is not only the first of its kind within the University, but within the state as well. Recently, via Bureau for Handicapped Children Memorandum, the second semester course was announced along with strong encouragement and endorsement. These are but two brief examples of "seed" money programming. Their selection was without any specific design other than demonstration.



C. Examples of Other Programs: With the Departments of Speech Therapy Curriculum at both the University of Wisconsin and Marquette University; support of the "Learning Disorders Institutes" on both University of Wisconsin campuses (Milwaukee and Madison); training and equipment grants to the rehabilitation unit at the Central Colony; and many other professional development programs, all of which have resulted in creation of new and/or more definitive programs for the cerebral palsied.

It has been said..."Necessity is the mother of invention". In our case "necessity" has been expressed by the needs of the cerebral palsied...immediate and multiple. "Invention" again in our case, can be characterized as the application of limited funds in a pump priming manner in an effort to diminish necessity.

U.C.P. of Wisconsin is sufficiently convinced on the wisdom of "seed" money programming. Experience has amply demonstrated that such programming has tended to create a "Domino reaction", resulting in: more federal involvement; greater state participation; and increased identity for U.C.P. of Wisconsin and the people it attempts to serve.

II. Supplementary Comments by Frances Fervoy, M.S., Chairman, Program Services Committee.

"As early as I can recall, even as a member of a local affiliate board, the state association, with limited funds, was engaged in some program or another involving the University, the Central Colony, D.V.R., or the Bureau for Handicapped Children, which always had long range implications. When I say "limited funds" I refer to years when our total state budget was no more than \$14-16,000.

If a philosophy pervades the functioning of our state committee than I believe it can best be summed up as follows: The program must have immediate results and effects for the cerebral palsied, if conducted within an institution, the program should be flexible and have a practical "phase" application for implementation in the community; the program should be acceptable to the various state agencies not only in philosophy, but re-inforced and continued by ultimate funding assumption; and finally, (as a state association program) adequate provision should be made for local affiliate participation, both in support of the program and as a recipient of the results.

No finer compliment can be paid a volunteer Program Services Committee, than to have an important state agency request that your association conduct a training program for professional staff. Such was the case of the State Bureau for Handicapped Children - on two different occasions. Once to conduct a three-day program for supervisory speech therapists from the public schools, and on another to conduct a six-week Bobath Workshop for orthopedic school therapists. In this latter example, faculty for this program was drawn from the Medical School at the University of Marquette and previously trained Bobath Therapists from the University of Wisconsin and the Central Colony. During the Speech Workshop, 95 therapists and supervisors were in attendance (1964). For the six-week workshop (1965) 17 P.T. and O.T. personnel from the orthopedic schools attended. The total cost of these two programs for U.C.P. of Wisconsin was a mere \$1300. The bulk of the professional honorariums, fees, supplies and printed materials, as well as continued salaries of these state employees, was borne by the Bureau. And I repeat...this was not merely a request to cooperatively "share" a program, but "would we organize and coordinate the conduct of this training program".

I must also hastily point out that our concentration within the area of professional development - institutional funding, etc., has not been at the sacrifice of direct client services. We receive and honor our share of requests for bracing, surgery, equipment, etc., but because of the relationships established, and the understanding by the professional members of our program Services Committee, we can and have

effectively called upon the Bureau, the Colony, and numerous other state and community services, to intercede. If not for the total client request, than at least for a major portion, thereby lessening the financial outlay by our state association. In reality is it so important to beat a foot-race to the client and provide him with a brace? Isn't the client equally served with a brace provided by the Bureau? And isn't this same client even further served by a therapist, teacher, nurse or physician, who as a recipient of a U.C.P. stipend attended the A.A.C.P. or some other program of enlightenment? In my years as a practicing speech therapist, I have yet to see a brace, wheelchair or the orthopedic surgeons incision visably labeled "furnished" by the State Bureau" or "Courtesy of the Central Colony".

If we have tended to concentrate within the arena of professional development, it has been because of the tradition of our state board, which demanded it. But even more importantly, the needs of the cerebral palsied have demanded it."

## TAPPING TAX FUNDS

Presented by  
Robert C. Bartlett, Director of Program Services  
UCP of New York State

The UCPA affiliates in New York State have utilized tax funds in many different areas of programming to serve the needs of both the child and adult, as well as the minimally and more severely involved individual.

To tap Tax funds, one must first become completely aware of all aspects of the program and the criteria which must be met to qualify for each program. The official agency inaugurating these programs are serving a dual function: to foster new programs, and to improve the quality of service being provided through rather stringent regulations.

Where an official agency is offering a "fee for service", UCP programs must be accredited by that particular state agency. Then UCP only needs to submit bills for service rendered. This relates primarily to medical rehabilitation and vocational rehabilitation services. When a program grant is requested, the official agency requires a grant proposal, and they have consultants who work with our agencies in refining the proposals if such programs are deemed feasible. One must be aware of the fact that in many of these areas of funding, there are priority listings for the available funds.

### I. Medicaid

The medical assistance to needy persons program (P.L. 89-97, Title XIX) was inaugurated by the New York State legislature in 1966. On a fee for services basis, this program provides financial assistance to qualified individuals for treatment and equipment (braces, shoes, and devices).

The responsibility for administering this program falls to the State Department of Health and Social Welfare, with the local public health official determining the medical eligibility and the local welfare district determining the financial eligibility. To qualify, the following factors are taken into consideration: annual income, savings, burial resource, and medical expenses. For the average family of 4 with a net annual income (less income taxes and cost of insurance premiums) with one individual providing the income, the income can be \$6,000 at the present time. Changes are being considered by the New York State legislature that will lower this amount to \$5,300 or \$5,500. Included in the program is also a chronic illness clause which is defined as follows: "A person who receives 60 or more consecutive days of care in a hospital or other medical institution."

To render services compensated under MEDICAID, a facility must have an operating certificate. To obtain an operating certificate the center must meet the criteria outlined in sub chapter "f" of the State Hospital Code regulating "Out of Hospital Health Facilities".

A recent survey carried out by the UCP State Association indicated that (from replies received) 11 affiliates operating medical therapeutic programs have 636 patients presently receiving medical assistance. In this program, the local county provides 25 per cent of the fund, and the state the remaining 75 per cent.



## II. Medical Rehabilitation Program

The Physically Handicapped Children's Program of New York is often referred to, in other states, as the Crippled Children's Program. Until the implementation of medicaid, this program provided all the funds for medical rehabilitation on fee for services basis. Now, all individuals must first apply for the medicaid program. If they cannot meet Medicaid criteria for admission, only then may they receive assistance from the Medical Rehabilitation Program. This program provides treatment and equipment, such as braces, crutches, and so forth. To qualify, one must meet standards which have been outlined for the program which are not quite as stringent in the area of income as those of the medicaid program. Often families will be assigned the responsibility of assuming part of the cost involved, with this program picking up the remainder.

The program also offers outpatient diagnostic and consultative services which are paid in full by the State Department of Health with federal funds from the Crippled Children's Services. No financial eligibility determination is needed for these services. The service must be approved by the local health official.

## III. Community Mental Health Service

The New York State mental hygiene laws created this act to encourage the development of preventive, rehabilitative and treatment services and to improve and expand existing community services in the field of mental illness, mental deficiency, epilepsy, behavior or emotional disorders. By local law, any county, outside of the City of New York, may establish a county Mental Health Board to cover the entire area of the county. Any city having a population of more than 50,000 may also establish such a group. It will be the responsibility of this board to review and evaluate community mental health services and facilities, and enter into contract for rendition for operation of services and facilities.

Four UCP affiliates are utilizing funds from this program to finance programs for the multi-handicapped within the area of mental health. The affiliates are required to submit a proposal for the program with anticipated budget expenditure and material supporting the program. The affiliates then provide 50 per cent of the funds which are in turn matched by the State of New York. The law also provides that local monies, which heretofore have been provided by affiliates, may be provided by a local government. This in turn is matched by the State government.

If our affiliates are to serve the total mental health of the community, as well as the needs of the multi-handicapped (IQ under 75), this area of funding is most logical. It necessitates our becoming involved and interpreting to the community Mental Health Board that there is a value and need for the services being proposed. We have found that many of these boards have not interpreted the legislation as serving our population, and they have restricted the monies to mental hygiene and mental retardation.

## IV. Private Schools for the Physically and Mentally Handicapped

Under Chapter 786, Section 4407 of the State Education Law, the State Education Department is authorized to contract with educational facilities for instructional services provided for handicapped children, when adequate public facilities are not available. The local school district must state that they are not providing school placement for these children. The state aid is limited "up to \$2,000" per year and can be applied to the cost of tuition only. These funds cannot be used to defray the cost of maintenance or other expenses.



For a number of years our affiliates have been offering educational services to multi-handicapped children who are excluded from public education programs, due to severity of involvement. These programs must have complete educational orientation and be structured the same as a regular special education program. In order to meet the requirements, many affiliates had to change their papers of incorporation to indicate education as a primary objective, thereby being able to call themselves a private school. The program must be daily and have regular full-time hours.

#### V. Space Rentals

A number of affiliates throughout the state lease space to the local Board of Education for operation of the special education program serving physically handicapped children. The income from this rental can then be applied to continued improvement of the physical facility or to areas of program services.

#### VI. Vocational Rehabilitation

This is a prime area of funding from both the State and Federal Vocational Rehabilitation agencies. Everyone should be aware of those sections under Public Law 565 which relate to expansion, alteration, innovation of services, workshop improvement, and planning. Just recently one of our affiliates received a grant under section 12 for the planning of a new vocational rehabilitation facility. This plan has now led to monies from other sections for development of the workshop itself. We have found the Division of Vocational Rehabilitation most cooperative in working with our affiliates in the development of new programs.

In the State of New York, there are two programs in existence which have been of tremendous assistance in our on-going program of service:

- A. Case Service Program - This program provides for 4 weeks of vocational evaluation and a subsequent 32 weeks of vocational training. The facility receives \$40 per week per client, and this amount may soon be increased. We know of instances where this money provides upward to 40 per cent of an agency's vocational rehabilitation budget.
- B. Workshop support Program - Based on the number of clients with a program, an agency can receive up to \$30,000 maximum per year for a three year period.

As with most programs, it has been our experience that the agency who has demonstrated an ability to provide quality service is in a better position to acquire additional grants for construction, expansion, and staffing of additional services. The most difficult point is probably getting started, and this means development of a proposal and selling it to "the powers to be." One must recognize that standards must be met in acquiring any assistance from tax funds. The local organization should be aware of the many responsibilities of becoming a recipient of governmental monies. Do not feel that this is a "pie in the sky" and you can handle it once you get it, unless you have a sound local organization.

## HIGH-RISK MOTHERS' PROGRAM

Presented By  
 Majorie Brush, Executive Director  
 UCP of San Francisco, California

This program was first reported at our National Conference held in New York, March, 1966. At that time there were also reports from the New York City Health Department and government public health officials from Washington, D.C. All stressed the availability of funds from the Federal Children's Bureau to local health departments to provide special medical and social services for mothers who are known as high-risk because of obstetrical and non-obstetrical conditions which might endanger their children, including the danger of brain damage, before birth. The program is known officially as the Maternity and Infant Care program under Public Law 88156. There is provision in the regulations under which this program operates for the use of local health department funds to supplement federal funds.

The San Francisco Health Department did not have sufficient matching funds available and the Board of Directors of the United Cerebral Palsy Association of San Francisco undertook to secure such funds and to commit community support for a five-year period. The reason for this policy on the part of the Board of Directors of the United Cerebral Palsy Association of San Francisco was that we are concerned with preventing neurological problems in children and, while there could be no immediate evidence that we were achieving this goal, it certainly was a step in the right direction to take advantage of this nation-wide program.

The Children's Bureau is gathering more and more information on the relationship between good medical and the social and economic care of pregnant women who fall into the category of those known to be likely to produce defective infants, in a nation-wide program.

We were able to secure the cooperation of the Health Council of the United Community Fund and through them received "K.O. polio" funds made available by the San Francisco County Medical Society. The UCP of San Francisco also committed funds received from a bequest to this project.

The Children's Bureau standards for obstetrical care, of course, are high. It was necessary for us to augment the salaries of a social worker and a nutritionist to obtain the superior quality staff needed. We also subsidize some of the mothers and their families to improve nutrition and provide them with the necessities, comforts, and protection that pregnancy demands.

Our experience with official social service departments reveal time lags, professional personnel changes that affect the service to individual cases, and rulings and regulations which conflict with the medical and social needs of the families. It has been the greatest satisfaction to be able to work with the social workers and the nutritionist on the program and give the families the services they need when they need it. For example, one mother was having contractions in the sixth month when the physician told her she must stop washing her other three children's clothes in the bath-tub. She was risking her own health and also the unborn child's. We provided a washing machine which cost the magnificent sum of \$35.00.

There are three more years for the five-year program which UCP is underwriting. These mothers live in the census tracts with the highest record of prematurity in San Francisco. Of course, these are the poorest districts in the city. By definition, "a high-risk pregnancy is defined as one with: 1. A history of obstetric complications such as miscarriage, fetal or neonatal death, prematurity, toxemia, dystocia or caesarean section; 2. a history of relevant medical complications such as diabetes, heart disease or tuberculosis; 3. primiparity prior to age 19 or at any age out of wedlock; 4. any parity after age 40 or, 5. no prenatal care for this pregnancy. The emphasis should be on both high-risk to the mother and to the child."

It has been difficult to get the mothers under medical care in the first trimester of their pregnancy. Also, the federal program does not provide for follow-up expect for those infants who were found to be high-risk. The maternal and child health services in San Francisco have not been able to pick up all the children and follow through with them, evaluating their health and welfare. The families in these census tracts tend to move frequently and seem to ignore the values of well-baby conferences.

It is quite possible that UCP will have to take up the problem of searching out these babies. It is also possible that the Children's Bureau will recognize that there is not enough long-term planning in the program as presently in operation. There is good evidence from the Kauai Pregnancy studies that pregnant mothers and their children can be protected by a concentration of good medical and social services.

It is well within the purview of a local affiliate of the United Cerebral Palsy Associations to promote health department and community backing for such a project, even if no money is available from the affiliate itself. Dr. Miller and Mr. Messner and Mrs. Haynes are all prepared to help local affiliates consider this kind of project.

I do not know if federal funds are now available for other cities. Certainly the fact that UCP of San Francisco was alerted to the availability of these monies, and had the opportunity of requesting the local health department to secure this program at the moment the funds were announced, was extremely important. In fact, it was the moment of truth.



## EPILEPSY PROGRAM OF UCP OF SAN FRANCISCO

The UCP of San Francisco was requested by the Health Council of the San Francisco United Community Fund to undertake an epilepsy program in this city. This request followed a period of study by the Health Council. Our association accepted the responsibility of exploring San Francisco's program needs concerning the epilepsies. As a result of this exploration, we received a Federal grant for a three-year period which permitted us to employ a health educator and conduct a program. It should be understood that there was no Epilepsy Society in San Francisco and that, at that time, the small chapters in other Bay Area counties had no professional staff. Both the Federal government and the United Crusade were interested in learning if a voluntary health agency concerned with neurological problem, such as cerebral palsy, which involves many children and adults with seizures, could provide a program emphasizing this phase of a neurological problem. (It is estimated that at least fifty percent of the cerebral palsied are subject to seizures.)

The United Bay Area Crusade now supports the epilepsy project of the UCP of San Francisco. We do not give all of the services to people with seizures that we give to the cerebral palsied, but we do take responsibility for getting every person we learn about, who is in need of help, into the proper community program. We believe that our work stimulated the development of a new federally supported epilepsy program at the University of California Medical Center. This new program will provide case finding, clinical services and research. It is not yet fully in operation, but the funds have been granted by the National Institutes of Neurological Diseases and Blindness.

Dr. Edwin L. Boldrey, Professor of Neurological Surgery, University of California Medical Center, is chairman of the Medical Program Committee of UCP of San Francisco, serves on several national advisory committees including the Medical Advisory Committee of the Epilepsy Foundation. He has discussed our program with national leaders in that organization and, of course, with Dr. Brewster Miller of our own United Cerebral Palsy Associations. Dr. Boldrey is convinced that associations like ours need broad concepts and policies regarding the problems of children and adults with neurological handicaps. The United Crusade is interested in fewer, separately operating, voluntary health agencies. More professionals in our field are showing that they respect and understand the inter-related aspects of the medical, social, and economic problems with which they are dealing.

Our epilepsy program is now in its sixth year. We have cooperated with the California Epilepsy Society in regard to State legislation. It is perhaps significant that the Bay Area Epilepsy Society, which went out of existence some years ago, gave us their funds of \$756.98 in August, 1966. While differences arise now and then, local chapters have pleasant relationships with UCP, as we all work in the Bay Area trying to help people.



## INTERDISCIPLINARY EVALUATION CLINICS

Presented by  
Richard Truax, Executive Director  
UCP of Minnesota

The time has arrived when UCP affiliates can become community coordinators rather than a referral service. The time has arrived when an affiliate with limited funds can take the initiative in organizing community programs which utilize the cooperation of other local agencies, branches of government and community action groups. We are studying and evaluating a two-year service program in the State of Minnesota which has been under the sponsorship and direction of UCP of Minnesota for the past fifteen months.

### The Individual With Cerebral Palsy

In most instances, the individual with cerebral palsy represents a complexity of abnormal neurologic and motor dysfunctions. This is frequently associated with emotional defects, intellectual defects, or convulsive disorders. Motor dysfunction is frequently in combined form with visual perceptual, speech or other sensory manifestations. In almost every instance, the individual with cerebral palsy is in need of specialized help and, if he is to be given adequate care and treatment, he must be understood completely. A vast amount of compiled data must be gathered concerning all of the complex facets of his development. The optimum approach to this evaluation is through an interdisciplinary diagnostic team, where specialists in several areas evaluate their findings and together recommend the best measures to help the individual in his future growth and development.

### Minnesota statistics:

In addition to United Cerebral Palsy of Minnesota, Inc., UCP is represented by seven local affiliates in the State of Minnesota. The seven local affiliates encompass 2/3rds of the population area of this state and 1/3rd of the geographic area. The state organization has up to this time had to assume the responsibility for any local programming then in 2/3rds of the geographical area of the state. A survey done a few years ago in the state suggested there were an approximate 4500 individuals with cerebral palsy in the state with an additional 350 to 400 persons with cerebral palsy being born in the state each year. Approximately 30% of the cases in the State of Minnesota are followed by either one specialist or a general practitioner for a specific medical problem only. In some rural counties over 2/3rds of the children have not been seen by a physician in years. Further statistical information provided suggests that not more than 20% of the children of this state have had the advantage of the interdisciplinary team diagnosis and evaluation to which we have referred.

## Minnesota Cerebral Palsy Evaluation Centers

### Project:

In December 1966, the state Board of UCP of Minnesota, Inc., upon recommendation from its Medical Advisory Committee, determined that a program of interdisciplinary evaluation, defining not only mental and physical handicaps but potential strengths and capabilities as well, was a basic and essential necessity to all other service programs for the individual with cerebral palsy. It was probably the most important element in considering future growth and development of the child with cerebral palsy. A very thorough study of the financial picture of the state organization in Minnesota, at that time, revealed that a project of this nature and scope would necessitate total participation and the cooperation by all of the local affiliates in the state and that only such cooperation could insure continuity of the program for the first full year.

### Scope: Primary and Satellite Clinics:

Initial involvement by UCP of Minnesota and its affiliates included an establishment of Evaluation Clinics in Minneapolis and Virginia, Minnesota, with immediate consideration for further developments at St. Cloud, Minnesota. The initially adopted plan, which still guides development of the clinic program in the State of Minnesota, was for the primary clinic to be established in Minneapolis, with all the other clinics in the state functioning as satellites to the primary clinic. Under this arrangement the primary center could supply medical and paramedical disciplines to the satellite clinics as the satellites would deem necessary and/or the satellite clinics could refer any of their patients to the primary clinic for any professional attention, which could not be made available to that patient at the satellite clinic.

### Financing:

For lack of any other significant experience factor, financing was by pro-rata distribution of the total budgeted costs for the program, based upon the population of the respective affiliate areas. The state organization assumed the pro-rata share of the budget for the non-affiliated areas and population. The consensus of the board was that there would be no recovery of fees or costs from patients or their families during the course of the first year, but that the prospect of recovery of costs from patients and families should undergo study and evaluation. It should be noted that positive steps are now being taken to explore the possibilities of financial cooperation in this program by Crippled Children Services in the State of Minnesota, by the Department of Special Education in conjunction with the respective school districts, through the Minnesota and the Metropolitan Health and Accident Insurance Association, through various state-wide clubs and organizations and through appeal to foundations for the direct support of such programs.

### Administration and Direction:

Responsibility for the direction of the primary clinic and each of the satellite clinics was given over to one of the medical professional people associated with the particular clinic. Administration of all clinics must be in conjunction with United Cerebral Palsy of Minnesota, Inc., and its affiliates. An Affiliates Joint Clinic Committee composed of one representative of each affiliate and one member from the state board meets on a quarterly basis with

the directors of the respective clinics. Any problems relating to administration of the clinics are jointly resolved at these meetings and referred to United Cerebral Palsy Directors for consideration.

#### Reporting:

Clinic directors provide the state office with a complete report, within the allowable ethical framework, on each patient whom they would have scheduled for evaluation. The reports on any patient residing within an affiliate area are directed to that affiliate for follow-up and on-going attention to any problems which the patient or his parents may have. Copies of reports are directed by the clinic director to the family physician, including all recommendations. In addition, copies of this report go to the public health nurse, to the school district, department of special education, and to any one else in direct responsibility for the future growth and development of the child.

#### Professional Involvement:

The interdisciplinary team at the primary clinic in Minneapolis consists of six physicians and six paramedical specialists. Included on the total team are a Pediatrician, an Orthopedic Surgeon, a Neurologist, an Oral Surgeon, an Ophthalmologist, a Psychologist, a Speech Pathologist, a Physical Therapist, an Occupational Therapist, a Social Worker, a Vocational Counselor, and an Educational Specialist. A clinic evaluation takes two days, with follow-up counseling. The evaluation process includes development of a medical past history, reports from other facilities, schools and doctors.

#### Parent Counseling:

Parent counseling at all clinics and in all instances, is conducted not later than one week after the clinic appointment and usually on the same day as the professional staffing session. The necessity of the attendance of both parents at the parent counseling session is stressed. One Medical Staff member is designated to counsel with the parents. This is usually the staff person most closely related to the major problems confronting the child. In addition to being advised as to the child's difficulties and being encouraged to assume a realistic attitude with emphasis on the child's maximum productive potential, parents are apprised of facilities and services available, in their local area, which will assist in carrying out recommendations of the interdisciplinary team. One staff or a volunteer person from the United Cerebral Palsy Affiliate usually attends the staffing and counseling sessions.

#### Follow-Up and Re-Evaluation:

Follow-up becomes a very essential part of the Evaluation Clinic Program. Unless there is adequate follow-up to ensure that recommendations will be carried out, there is little reason for the evaluation and the recommendations. In addition to reports being filed, as previously noted, with the family physician, the public health nurse, the school system, and other professional people concerned with the future growth and development, two procedures are utilized to insure that each child will have proper follow-up. Each child seen at the clinic is assigned to one medical or paramedical specialist for proper follow-up. This person is provided with a file copy of all information and recommendations and is charged with the responsibility of seeing that recommendations are carried out.



In addition, each patient is scheduled for re-evaluation, most frequently on a three, six or twelve month basis. In the case of a patient from an unaffiliated area, affiliate staff or volunteers are assigned for contact and counsel with the parents and patient.

Cooperative and coordinated programs are developing with other agencies in the community as the result of recommendations arising from clinical evaluations. We are referring patients to Minnesota Society for Crippled Children and Adults for orthopedic appliances and for summer camping programs. We are referring patients to the Easter Seal Society for speech counseling. We are referring patients for physical therapy to established centers in the area, and have recognized the possible need for a mobile therapy service in the state. We are developing a legislative program directed to residential care for the adult individual with cerebral palsy and pre-school programs for children with physical handicaps, because of problems that have been brought to our attention through the Minnesota Cerebral Palsy Evaluation Clinic Program.

Conclusion:

This program has allowed us to give some service to that 40% of the population in our state, that is one million people plus, who up to a year or so ago had no particular reason to ever know that our organization existed. It has allowed us to affect some semblance of state-wide application of program.

We have set certain goals which we wish to obtain through this assessment and re-evaluation of programming:

1. To assume the basic responsibility for all persons with cerebral palsy throughout their lifetime, forming an active partnership with parents;
2. Make available to the cerebral palsy person a lifetime of broadly divergent services which will allow each such individual to reach his maximum potential.

The question now before us is whether or not United Cerebral Palsy under the present structure can truly serve all persons with cerebral palsy throughout their lifetime, plus allowing such individual to reach his maximum potential. Possibly we create the necessity for an immediate second step, which will allow for a vertical re-assessment and re-evaluation of structure which will enable us to obtain the very commendable goals which we have established for ourselves.



RURAL SATELLITE CENTERS -  
and  
USE OF VOLUNTEERS

Presented by  
Flonnia Taylor, ACSW, Executive Director  
UCP of The Bluegrass, Kentucky

Three aspects of the United Cerebral Palsy of the Bluegrass (UCPB) program may be considered unique in that they had not been developed extensively in UCP affiliates at the time UCPB was organized: (1) satellite centers; (2) volunteer or allied specialists; and (3) volunteer consultants. These have been inter-dependent and inter-related since the beginning of the affiliate and have grown as the total organization has grown.

The UCP of the Bluegrass, organized in 1956 and chartered in 1957, started its program of services in 1958 with a mobile team of volunteers and one paid professional person. The Bluegrass affiliate is the direct result of Mr. Sherwood Messner's study of services to the cerebral palsied in Central Kentucky, followed by his guidance in the organization of a Board of Directors.

I. Satellite Centers or "Rural Development Centers"

Lexington is the hub of educational, medical, and other professional services, not only for the Bluegrass section in Central Kentucky but for all of Eastern Kentucky. It would have been less difficult to establish one central program as had been done in Louisville to serve several counties. The UCPB Board decided, however, to experiment with a mobile unit, giving at least one day a week in each of five counties, thus carrying services closer to children in rural areas.

II. Volunteer Staff

During the first year we had one paid staff member (the Director who was a professionally trained medical and psychiatric social worker) who trained 83 volunteers to work directly with children. These volunteers were professional nurses, practical nurses, teachers (some college professors), social workers, speech therapists, nutritionists, housewives, and just "good" civic minded people. Each volunteer had to be certified by the agency. Such certification was given only after four 3-hour sessions in an organized training class. These classes were held at specified periods and were well advertised. The training staff consisted of a Board member who welcomed the volunteers and gave the history of UCP, a nurse who discussed safety procedures, including specialized care of wheel-chair patients, etc., a social worker who helped the volunteers to think about their own motives, their contribution of service and their remuneration in satisfaction; and the social worker also helped them to consider the parents of handicapped children and the increased family problems that are always magnified by illness, helplessness, and frustration. Finally, qualified psychologists and teachers discussed the child's needs in relation to developmental patterns, social and emotional behavior, and basic educational growth.

Actual demonstrations showed what toys to select for certain kinds of training and why, showed how to assist the child in using the toys, and illustrated how to stimulate the child to want to use these tools in the serious business of muscle control, eye-hand coordination, brain-body communication and verbal communication.

Volunteers who came into the program afraid of doing something wrong remained to become secure in the help they offered. They also liked the recognition received through publicity and awards. During the past nine years UCPB has trained and used more than 1000 men and women in all of its Centers. Two of the results of this kind of training for the volunteer are personal growth in understanding all children and ability to interpret the agency as a volunteer staff member. These ideas were aptly expressed by a professor at Eastern Kentucky University when he wrote "From the course I learned a great deal about normal child development, about the needs of all children, and now I feel I am a better father because of this knowledge. At the same time I feel I can sincerely interpret to others in my neighborhood what UCPB is doing and how important this service is to the entire community. I know now that cerebral palsied children are attractive, lovable personalities who can learn, if given adequate opportunities."

Volunteer interpretation of the agency is the best publicity for fund drives that any agency can have.

As its volunteer program grew so did UCPB. five centers were established in fifteen counties in 1958. Of these the public school took over two after the "helpless" children had learned how to walk, talk, and work together in a group situation. The schools also took over the certified teachers UCPB had recruited and trained. UCPB started again from "scratch" by selecting a new teacher and evaluating new children. We expect this group to become a part of that public school system by 1970. Some children from all of our units have moved into regular classrooms where they are holding their own with normal self-controls and how to communicate. UCPB still has four centers outside of Lexington and at present a paid staff of sixteen people. These centers moved from a one-day type of center after the third year to a five-day per week program with a local teacher in charge. The paid mobile staff which supplements the teachers, the teaching assistants, and volunteers consists of a social worker and a speech therapist.

Local public health nurses and nutritionists are also used in the program as well as volunteer specialists in music, physical education, recreation, and drama.

All satellite centers are under the administration of UCPB, and the staff attends meetings in the central office. All centers have county representatives on the UCPB Board of Directors. All campaign funds are placed in the UCPB treasury and all bills are paid by the UCPB treasurer.

#### Lexington Central Office

In Lexington four centers are run simultaneously with the same type of staff. The volunteer program in all of our centers can be divided into four parts:

1. the allied specialist which has been described
2. the consulting specialist
3. the club sponsors
4. the general volunteer who assists in fund raising, publicity, and in dozens of other ways.

### III. Consultants

The consulting specialist is worth thousands of dollars to us. For example, a psychologist is used in staff development and in giving tests to children whose parents cannot afford to pay for the service; a psychiatrist serves in much the same way, even giving therapy when needed; orthopedists and optometrists, neurologists and dentists, physical therapists and occupational therapists, pediatricians and social workers help to increase our services through their hours of consultation with staff and actual treatment of carefully selected indigent children.

Through the efforts of a volunteer professional consultant UCPB obtained the attention of the immediate past Governor of Kentucky and his Commissioner of Finance who gave \$50,000 for a two-year research program. The money goes through Eastern Kentucky University which loaned one of its professors to actually direct the research. We hope someday to present in writing the way we evaluate and the methods we use which have brought dramatic and incredible results. We give credit to the highly skilled and dedicated professional staff, their assistants, and consultants for the 113 children who are now in regular public school programs who would never have been accepted without this pre-school training. Many of these children could neither walk nor talk when they were admitted to UCPB, while others were so hyperactive they were considered uncontrollable.

Agencies that need volunteers must frequently permit staff to serve as volunteer consultants to other groups. The UCPB Board of Directors encourages this type of reciprocity.

### IV. Sponsors

Clubs make it possible for UCPB to run a very expensive program on a small cash budget. Each center is sponsored by one or two clubs. These clubs furnish testing materials, pay some fees for families who cannot pay them and provide special equipment. For example, the Metropolitan Woman's Club not only requires all new members to serve as active volunteers within the agency for one year but also furnish the room which is named for the club and purchase from \$300 to \$800 worth of equipment each year.

### V. General Volunteer

The general volunteer may be retired person or a housewife who needs to feel useful in the community and is willing to serve as office hostess (answer the telephone and greet visitors with a cup of coffee or tea) or who helps to raise money in her neighborhood. The general volunteer may be a seamstress who will make uniforms for the staff or cover relaxing chairs or pad a standing table. A general volunteer may be a man with a home work-shop which he will use to make tables and chairs, build cabinets for coats and supplies.



Through a volunteer who was alert in the interpretation of UCPB's program and its results, the agency was offered some free time by a local television station; that was four years ago last April and we are still presenting a weekly 30-minute program which is called "That Special Child." Not only is it given a special format, special theme music, etc. but is publicized through the week along with commercially sponsored programs. It is difficult for me to believe that the show's rating is fifty percent of all viewers at that specific hours.

VI. UCPB is small but it manages to serve as a vocational rehabilitation training center for selected adults and as a field placement center for graduate social work students from Kent School in Louisville and for practice teaching by students in education at the University of Kentucky and Eastern Kentucky University. The agency staff works closely with the University of Kentucky Medical Center and with the College of Education as well as with Eastern Kentucky University. One UCPB staff member serves on the University of Kentucky Medical Center Diagnostic Center, another serves as a consultant to the Kent School of Social Work, another serves as supervisor of student teachers, and still another teaches class in special education at the University of Kentucky and Eastern Kentucky University.

### Conclusion

In conclusion, I must add that Parent Education Groups led by a social worker has no doubt been one of the important keys to the success of UCPB. All mothers of new children are required to attend one series of eight meetings unless they are employed (in such cases the social worker sees the mother individually in her home at frequent intervals). The fathers have a six weeks series on Sunday afternoons. It has been amazingly gratifying to find that all the parents have insisted on follow-up series -- and some have come to as many as eight in a four year span. These meetings are in addition to the parents' club bi-monthly meetings which the parents run without staff. There is little doubt in the mind of the Executive Director of UCPB that as long as the Board of Directors is conscious of community needs the satellite centers will continue and perhaps increase, the volunteer program will remain a driving force, and consultants will continue to be used in the in-service training program and in treatment wherever possible in addition to the service rendered by a medical and professional advisory board.



## AFFILIATE HISTORY RELATED TO THE ROCHESTER REHABILITATION COMPLEX

Presented by  
Winnifred Fletcher, Executive Director  
UCP of The Rochester Area, N. Y.

The UCP of the Rochester Area has completed twenty-one years of service to the cerebral palsied person. At the request of U.C.P.A. National, we have taken a look at this service and how it measures up to the mandate:

- 1) To assume basic responsibility for all cerebral palsy throughout their lifetime in partnership with their parents.
- 2) To make available to the cerebral palsied person a lifetime of broadly divergent services which will allow each such individual to reach the maximum of his potential.

Our Cerebral Palsy Association was first organized by a group of parents to request from the University Medical Center of Rochester an adequate medical service for diagnosis and supervision of a treatment program. The Medical Center responded to this call by establishing a Cerebral Palsy Diagnostic Clinic comprising a team of medical specialists in pediatrics, orthopedics, neurology, psychiatry and psychology. They also recommended the establishment of a treatment center with physical, occupational and speech therapy available to carry out the recommendations of the team.

Funding for such a project and program was received, by the efforts of our medical advisory board and the Board of Directors of this clinic, from a New York State Grant for the Diagnostic Team; and for the treatment center from the Rochester Community Chest. As the New York State Grant diminished an increase in our Community Chest budget was allowed. The Community Chest has always supported our projects to the limit of our requests - this support carefully managed has been a great source of stability for our program.

In the fall of 1948 a nursery school for the children from 2 years of age was added (with qualified supervision) which greatly enhanced our knowledge of the pre-schooler - and enabled the staff to give to the parents valuable aid and instruction in the treatment and handling of their children.

In 1953 a certified teacher was employed to continue the education of our children who were not eligible for inclusion in the public school special classes or local public schools. Five years later this classroom was staffed by a teacher provided by the City School District of Rochester with a request for the inclusion of a regular kindergarten for all physically handicapped children of the community.

Medical supervision by some members of the diagnostic team is carried over into the Clinic program, so that constant review of medical needs or referral for further diagnostic studies is possible.

All through these years a recreational and socialization program has been offered for the young cerebral palsied adult. It began as once-a-month club meeting in 1947 - and in 1955 was expanded, with the building of a new facility, to three afternoons a week.

Medical Social Service is a companion to our diagnostic and clinic programs.

Volunteer services from a variety of sources: - our own volunteer chapters, Junior League, Junior Aides for the Handicapped, Girl Scouts, Teen-agers, and many others - have given thousands of hours - saving us uncounted dollars - and providing additional services not allowed in budgets.

Parents' programs have been offered in many forms. A strong Association has guarded our policies and offered to its membership programs of educational and social variety.

After ten years of planning and hoping - within the next two months, U.C.P. of Rochester is moving to a new Rehabilitation Complex-the Al Sigl Center. Seven autonomous agencies, all members of the Rochester Community Chest, will be housed under one roof allowing for easy access for communication, cooperation and above all, modern services and facilities for our clients.

U.C.P. of Rochester has a stable and growing program in the number we serve and through services we offer, but we fall short of our mandate. In reviewing the program with members of the medical advisory group, the staff, and the Board of Directors, the following recommendations were made:

- 1) That a concerted effort be made to affect more early referrals of children with cerebral dysfunction. An adequate program is available for diagnosis and treatment - and for parental instruction and training. However, this information is not widely known of, if known, not used for a variety of reasons. There are great possibilities inherent in the Al Sigl Center for teaching purposes at the intern and resident level. A renewed effort must be made to disseminate information.
- 2) Our pre-school and kindergarten program is of good quality in partnership with the City School District of Rochester and allows for the investigation of the pupils educational potential and comprehensive recommendations for further education and/or training to the appropriate agency. We should, however, follow more closely the children in these schools and endeavor to make known to these faculties - the many needs of the children so that schooling programs can be adapted to these needs.
- 3) Our programs for the severely physically and mentally handicapped seem adequate. Severely mentally retarded child are referred at the appropriate time to the Day Care Training Center, Al Sigl Center Agency.
- 4) Our program for the teenager and adult only encompasses the severely physically handicapped after all other services of the community have been tried. We have relied upon other agencies in the community i.e. Association for the Retarded, the Rochester Rehabilitation Center in partnership with the State Division of Vocational Rehabilitation to evaluate for vocation potential and supply workshop opportunities. Workshop opportunities have been particularly lacking especially for sheltered employment to the cerebral palsied person. With our move to the Al Sigl Center, the inadequacies of space will be overcome and the workshop agencies will be better equipped to offer a more workable program for our clients. More medical services for teenagers and adults should be available - especially by an evaluating team and at regular intervals, so that no opportunity for care could be overlooked.

- 5) We have been blessed with devoted services from a well-experienced medical team. We hope our proximity to the Medical Center will bring more doctors and paramedical people in closer contact with our program and inter-discipline communication will be improved as they become more familiar with the many facets of the program.
- 6) Permanent residential opportunities for the non-mentally retarded physically handicapped adult are non-existent, except for the Monroe County Home and Infirmary. Such a residence has long been the subject of committee deliberations. With the possible establishment of a temporary residence for adults in the near future - maybe this is a stepping stone to our dream of a permanent residence facility.
- 7) Some thought was given to more counselling for parents and the need for a full-time social worker was stressed. In this way you could promote group work with parents and more participation on an individual basis.

Our association with U.C.P.A. National through the State Association has been close and always productive. Several of our volunteers have been privileged to work in officer capacities. This association broadens our horizons, disseminates valuable information, gives us renewed hope with research programs, and makes us take a penetrating look at what we do and how we do it.

By 1973, we should have a much better report.

## AGREEMENT WITH THE VISITING NURSES ASSOCIATION

Presented by  
Barbara Green and Frazer Banks, Jr.  
UCP of Pensacola, Florida

Due to the limitation of funds and the unavailability of a social worker in the Pensacola area, a working agreement was made with the Visiting Nurses Association for the use of one of their nurses for twenty hours a week to carry out the necessary home and parent contact work vital to the communication between the home, the Center (Staff), Medical Director and Medical Staff. At the time, VNA could justify the need for a nurse for only half time, and were able to let her work for the Center half time.

After a year and a half of limited time available to the Visiting Nurse many expected problems occurred, but in turn many unexpected benefits also appeared. Professional advice, after home visitations, was accepted more readily by the medical staff, and a closer relationship between the Visiting Nurse, the Center Staff and the teachers was established. However, more knowledge in the psychological field would be helpful. It would have been further advantageous if our Visiting Nurse could have been able to attend a training program such as the one offered at Indiana University on Cerebral Dysfunction.

In spite of the limitations of time and training of which we had to make the best, the general education and experience of Visiting Nurses provide an added dimension to the helping team.



## DEVELOPING DENTAL SERVICES

Presented by  
 Clare Porter, President  
 Ruth Mitchell, Executive Director  
 UCP of Northeastern Maine, Bangor, Maine

This affiliate was approached by a dentist in the community who was interested in organizing a regular program of dental care for cerebral palsied children. This is undoubtedly a direct result of Mr. Ernest Weinrich's presentation at a Lion's Club meeting which the dentist attended.

A committee was organized to explore this and consisted of: first dentist, a second dentist on UCP board, the Cerebral Palsy Center's social worker, executive director, and an additional board member.

The following format was conceived and implemented:

- A. Letters were sent to all families whose children receive UCP services explaining this new service. Enclosed was a form asking for the child's name, date of last dental appointment, and if it was a routine or emergency visit.

When these were returned (after some prodding), they were sorted: (1) families who wanted to be a part of the clinic and (2) those who were happy with their child's present dental program and did not want to change.

- B. The first dentist contacted a selected number of other dentists in the County Dental Society and asked if they would participate. Results were gratifying. For children living outside of Bangor, a dentist was contacted in their home town.
- C. Children were then assigned to one of the participating dentists to be seen in his office if office treatment were possible. This would be on a regular basis. Fees charged to parents would be considerably less than regular and would be billed directly to them by the dentist.
- D. Great care was made by the Cerebral Palsy Center's social worker to see that parents understood the details of this arrangement.
- E. Up to the present time, all children have been able to be treated comfortably in a dentist's office. Should a child need hospitalization and general anesthesia for dental work, this will be arranged with a local hospital which has such a dental facility. The expense of this arrangement, though, is a deterrent.
- F. Follow-up is underway at the present time. The Cerebral Palsy Center is providing the dentist-in-charge with a list of children and their assigned dentists. His office will call these dentists and determine:

1. Have parents contacted their dentist or brought child for treatment.
2. Have parents paid the fee.

The social worker will talk with parents in those cases where the answer to either question is "No".

We do not feel the participating dentists should have to write-off these accounts, and we will try to make arrangements with parents for longer payment time. We may also assume some or all of the financial responsibility. Since the value of such a program is its regular and on-going treatment, this should not be jeopardized.

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## GUIDELINES: HOME SERVICE PROGRAM FOR HANDICAPPED

### A COOPERATIVE PROGRAM OF THE PENNSYLVANIA ELKS STATE ASSOCIATION AND THE UNITED CEREBRAL PALSY OF PENNSYLVANIA

Presented by  
Charles Mitchell, Jr., Chairman  
Home Service Committee  
UCP of Pennsylvania

#### I. The Plan (Effective August 1, 1967)

To provide and expand services to the cerebral palsied and other handicapped persons throughout Pennsylvania:

1. ESTABLISH Home Service Units throughout the state of Pennsylvania staffed with qualified Home Service Directors to provide "home service care" to the cerebral palsied and persons with other handicaps. Each unit shall consist of a trained professional person and a vehicle.
2. OPERATE this service through local Affiliates of the United Cerebral Palsy of Pennsylvania, who will administer the program, cooperating with other agencies and services.
3. DEVELOP strong local Elks interest in the problems of the handicapped by their regular contact with the program in their local area and provide a service in which every Elk can help.

Local Affiliates of the United Cerebral Palsy of Pennsylvania will direct, operate, manage and maintain the Pennsylvania Elks Home Service Program for which the Pennsylvania Elks State Association provides the financial support and the United Cerebral Palsy of Pennsylvania provides coordination and assistance of a professional and technical nature.

#### II. The Program

1. The Pennsylvania Elks State Association will support a number of units each year. Financing will be by the Pennsylvania Elks Major Projects Inc. through the generosity of the Elks of Pennsylvania.
2. A Coordinating Committee of the State Elks and the UCP of Pennsylvania will review costs and operation of the program periodically.
3. The United Cerebral Palsy of Pennsylvania Local Affiliates provide "home service care" on a day-to-day basis.
4. Persons living within the Home Service Unit area may be eligible for service if he or she meets the following qualifications:
  - a. Referral of the patient must come from a physician, a hospital, related medical personnel or any recognized Health or Welfare Agency either voluntary or governmental. In instances where referral does not come from these sources a physician or a clinic will be consulted.



- b. There must be some reasonable expectation that the patient or his family can benefit from the program.
- c. There must be some indication that the patient or his family is not receiving similar services elsewhere.
- d. No fees shall be charged to persons receiving service from the program. The need of the patient shall be the chief consideration without regard to race, creed, color or financial circumstances.

### III. The Procedure:

#### 1. The Coordinating Committee

- a. A Coordinating Committee shall be established consisting of 4 directors of the Pennsylvania Elks Major Projects, Inc. and 4 members of the United Cerebral Palsy of Pennsylvania Home Service Committee.
- b. The Executive Director of the United Cerebral Palsy of Pennsylvania and the President of the Pennsylvania Elks Major Projects, Inc. shall serve as ex-officio members of this committee.
- c. The Coordinating Committee shall meet semi-annually during the Annual State Elks Meeting (usually in early June) and at the time of the UCP of Pennsylvania Annual Meeting and Conference (usually in early October). Other meetings will be scheduled as determined by the Coordinating Committee.
- d. (1) The Chairman shall be elected by the Coordinating Committee at the Annual Elks Meeting, to serve a term of one year.  
(2) The Chairmanship shall alternate between the two organizations.  
(3) A quorum shall consist of at least two members from each organization.
- e. The Coordinating Committee shall be responsible for:
  - (1) Review and approval of applications of local Affiliates of the UCP of Pennsylvania for new units.
  - (2) Review reports on the operation of the program.
  - (3) Make recommendations for improving the program.
  - (4) Define the basic financial needs of the program annually.
  - (5) Review and approve plans for interpreting the Home Service Program at the annual workshops and annual meetings of the Pennsylvania Elks State Association.

#### 2. Finance

- a. (1) An initial operating advance of \$1,000 from the Pennsylvania Elks Major Projects, Inc. shall be made to each Affiliate having a Home Service Unit.

- (2) A special account shall be established by each Affiliate which shall serve as a revolving fund for financing the program.
  - (3) The Pennsylvania Elks Major Projects, Inc. will remit monthly payments to Affiliates for operational costs of the local Home Service Unit.
- b. All expenditures from the special account will be the direct responsibility of the local Affiliate Executive Director.
  - c. Monthly expense reports including invoices are to be prepared by the Home Service Director in conjunction with the local Affiliate Executive Director and submitted by the 15th of the month for review and reimbursement by the Elks Major Projects, Inc. (Three copies to the UCP of Pennsylvania Office - two of them for the Elks Major Projects, Inc. and one for the UCP of Pennsylvania Office. A fourth copy should be retained by the Affiliate.)
  - d. Adequate general liability and other appropriate automobile insurance shall be carried in accordance with standards set forth by the Coordinating Committee.
  - e. The Elks Major Projects, Inc. shall be responsible for the following Home Service Unit expenses:
    - (1) Mal-Practice Insurance
    - (2) Operative costs of vehicles and the salaries and related expenses of Home Service Directors.
    - (3) Professional literature for the treatment of the handicapped.
    - (4) The Annual Elks Workshops and Annual State Elks Meeting and UCP meetings, workshops and conferences approved by the UCP of Pennsylvania.
    - (5) Public relations, such as photographs, advertising and publicity.
    - (6) Local Elks projects, such as dinners and transportation.
  - f. All expenses except those listed above in "e" are to be paid by the local Affiliate.

### 3. Personnel

- a. Each Home Service Director shall be a Registered Nurse, an Occupational Therapist, a Physical Therapist or a person having equivalent qualifications.
- b. A job description for each of the Home Service Directors shall be prepared by the local Affiliate and shall be subject to the approval of the Home Service Coordinating Committee.
- c. All Home Service Directors shall have a starting salary of at least \$5,000 per year. Salary ranges and increments shall be established by each local Affiliate.

Because of budgetary requirements of the Elks Major Projects, Inc. all salaries and increments must be examined and approved by the Coordinating Committee.

- d. Each local Affiliate shall be responsible for the recruiting, employing, training and supervision of the necessary staff persons to work in the Home Service Program.
- e. All unit employees shall be subject to the same "Personnel Practices" employed by the local Affiliate operating the unit. Such practices shall cover vacations, sick leave, work hours, retirement, right of appeal, insurance, special leaves, etc.
- f. A Home Service Consultant position on the United Cerebral Palsy of Pennsylvania staff should be established as soon as funds are available from any source.

4. Communication Between the Elks and the UCP of Penna. and its Affiliates

- a. No Affiliate of the UCP of Pennsylvania, nor any employee or representative of such Affiliate, shall communicate directly with any member or representative of the Pennsylvania Elks State Association with respect to the Home Service Program.

All communication relating to the Home Service Program shall be directed to the Coordinating Committee of the Pennsylvania Elks State Association and the UCP of Pennsylvania.

5. Functions of the UCP of Pennsylvania

- a. The UCP of Pennsylvania shall be responsible for the coordination of all aspects of the Home Service Programs, for providing consulting services and assistance of a professional or technical nature to its local Affiliates with respect thereto, and to maintain liaison with the Pennsylvania Elks State Association.
- b. In order to permit the UCP of Pennsylvania to perform its responsibilities properly, all local Affiliates conducting Home Service Programs shall keep the UCP Home Service Committee fully informed concerning the operations and functioning of their programs.
- c. The UCP of Pennsylvania shall provide such local Affiliates with all information which will be helpful to them in conducting their Home Service Program.

6. Elks Vehicles

- a. Vehicles purchased by the Elks for the Home Service Program shall be assigned to local Affiliates in accordance with action by the Coordinating Committee.
- b. Elks vehicles may be used by Affiliates for traveling to conferences and other meetings both in-state and out-of-state that are not specifically related to the Home Service Program but are related to the work of the Affiliates, provided: (1) The vehicle can be spared at the time of the trip and (2) the operating costs for the trip are paid by the Affiliate.

(Note -- In addition to providing transportation that might not otherwise be readily available, vehicles provide good public relations and interpretation opportunities for the Pennsylvania Elks State Association.)

- c. Use of the Elks vehicles for special occasions such as parades provides good public relations. It is important that Elks Lodges request the use of the vehicles through the Pennsylvania Elks State Association secretary for special occasions 2 to 4 weeks prior to the event and that the number of requests be reasonable.

They should also be requested only for very special occasions. Vehicles are sometimes scheduled for specific programs weeks in advance.

In view of the time involved it is suggested that an Elk member drive the vehicle on such occasions, if possible.

## 7. Reports

- a. Four copies of a quarterly report are to be prepared by the Home Service Director in conjunction with the local Affiliate Executive Director, reporting the activities of the unit for the three month period. (Three copies to the UCP of Pennsylvania Office - two of them for the Elks Major Projects, Inc. and one for the UCP of Pennsylvania Office. A fourth copy should be retained by the Affiliate.)

The UCP of Pennsylvania Office will send photo copies to the UCP of Pennsylvania Home Service Committee and to the UCP of Pennsylvania President.

NOTE: These procedures will be reviewed and reissued annually to all Affiliates with Home Service Units.

## IV. Practical Assistance to Families may be directly provided through this program in some (or all) of the following ways:

1. Assistance in securing adapted furniture and assistive devices in the home: There is a growing array of special equipment available to make the handicapped person more comfortable and functional. Patterns, designs and samples may be shared with the families of the handicapped when it appears that an individual may be aided by such equipment.

This service relates chiefly to "non-prescribed" apparatus, although qualified Home Service personnel may also develop or otherwise obtain prescribed equipment for sitting, standing, etc.

2. Assistance with "Home Care" problems: Special technical assistance may be provided with such problems of home care as feeding, toilet training, adapting clothing, recommending therapeutic toys, lifting and carrying, bathing and a variety of similar problems. Home Service personnel may directly provide such assistance or call upon other professional people to do so.
3. Referral and follow-up services: Home Service personnel are trained to know of general and specialized services for the cerebral palsied throughout the State. They regularly attend seminars and training sessions to up-date their information. They know the medical, educational and vocational resources, and procedures for obtaining services. They are prepared to accompany families to clinics, institutions and workshops



in order to help them more adequately plan for future assistance. Continuous contact is maintained with individuals and families whether or not essential referrals are made.

4. Counseling: In circumstances where it is appropriate, the Home Service person may counsel a handicapped individual or his family concerning a variety of practical problems, such as: social security and tax benefits for the handicapped, institutional placement procedures, home recreation activities, and diversional pursuits. Physicians and clinic directors may also use Home Service personnel to interpret clinic findings to individuals or their families.

Since the professional background of each Home Service person carries competence in a specialized area (teaching, nursing, physical therapy, speech therapy or occupational therapy), he may provide more detailed counseling in the area of his own training.

The program is intended to provide a regular and continuous relationship between a Home Service Director and the families of the handicapped. It is further intended to provide an additional resource to other agencies, organizations, or individuals who may be working with a handicapped person.

## HOME SERVICE PROGRAM - 1967 PROGRESS REPORT

Presented by  
David A. Young, Executive Director  
UCP of Lima and Allen County, Lima, Ohio

### I. Why Was The Home Program Begun?

A very common problem experienced by most cerebral palsy clinics (and even more so in predominately rural areas and communities where no clinic is available) is that there are not enough therapists to work with every child in need. Thus, the more cerebral palsy patients there are in a disadvantaged area, the less therapy and treatment each child gets. The Lima and Allen County Clinic is more fortunately located because it has the facilities for treating the cerebral palsied and neuromuscularly handicapped. The surrounding areas are more disadvantaged because the treatment is needed, but there is an inavailability of therapists, specialized medical personnel and an inaccessibility to an organized Clinic facility. A definite gap in service was evident.

### II. What Are The Objectives of the Program?

The primary objective of the Home Service Program is to provide comprehensive medical management and related therapeutic programs to cerebral palsied, neuromuscularly and similarly involved children living in "out-lying and disadvantaged areas". Since comprehensive and coordinated services are available at The Lima and Allen County Clinic, the problem at hand is to organize these facilities that are already available in such a way that both the persons residing convenient to the Clinic as well as those persons living in areas not so convenient and lacking in professional facilities can benefit from therapy and other management advocated by researchers and prominent specialists in the areas of physical medicine and rehabilitation for the cerebral palsied.

By utilizing existing out-patient therapy facilities in the Lima community and at The Lima and Allen County Clinic, the purpose and intent of the Home Service Program is to provide a facility for the team approach of specialists, pooling their findings and outlining a program of management, for the cerebral palsied both in Lima and in the out-lying communities.

### III. What Areas Were Emphasized and Progress Noted During 1967?

Areas of emphasis were:

1. Case Finding and Public Education
2. Comprehensive Diagnostic and Evaluation Services
3. Therapy, Treatment and Placement

### IV. Case Finding and Public Education

With the initiation of the Home Service Program, programs were held to inform public health nurses and various other community agencies who have contact with handicapped children in a 12 county area.

A Seminar and Workshop for public health nurses and other professional persons was conducted at Lima Memorial Hospital in Lima, Ohio. More than 75 public health nurses, therapists and health and welfare workers from the surrounding counties attended this Seminar.

A second Seminar and Workshop is planned for Saturday, February 10, 1968, entitled "Education of the Neurologically Handicapped". It will again be held in Lima, Ohio in the Senior High School in cooperation with the Ohio Department of Education, Division of Special Education and The Lima Public School System. Attendance is expected to exceed 100 persons.

In addition to conducting public education and awareness seminars, information concerning enrollment and admission to the program was forwarded to all of the various county health departments and public health agencies along with educational literature and pamphlets on cerebral palsy.

Another area of public and professional education has been the conducting of a Monitor Training Program for training and certifying baby-sitters for handicapped children in the surrounding areas. In April 1967, a Monitor Training Program was conducted at The Lima Memorial Hospital School of Nursing for 3 consecutive Saturdays. On completion of the program 47 girls were graduated and received certificates. To date 102 girls, fifteen years old or older have been trained and certified as qualified Cerebral Palsy Monitors or baby-sitters. Certified Cerebral Palsy Monitors reside in Cridersville, Findlay, Lima, Minster, Wapakoneta, Bluffton, Ada, Lafayette, Delphos, Ohio. A directory is being published and mailed to all the health and welfare agencies in the Home Service Program Area.

#### V. Complete Diagnostic and Evaluation Services

During 1967, 16 new referrals were received with requests for diagnostic and evaluation services from Lima and the surrounding areas. These 16 referrals represent 6 counties.

Diagnostic evaluations included an initial pediatric evaluation, social case history and other evaluation in the areas of orthopedics, ophthalmology, dentistry, neurology, psychology, speech and hearing therapy, occupational therapy and physical therapy. Upon completion of each of the diagnostic evaluations recommendations were made for treatment, placement into institutions, enrollment on a home program or referral to other agencies. Of the 16 new patients referred for diagnostic and evaluation services, the following dispositions were made:

Home Service Program and/or regular therapy	13
Evaluation still pending	1
Dismissed	2

#### VI. Therapy and/or Placement on the Home Program

Upon completion of the diagnostic evaluations, those children for which recommendations were made for therapy on a home treatment program are re-scheduled and evaluated at regular intervals of 3, 6 or 12 weeks, depending upon the individual situation. The Clinic Nurse-Home Visitor and family are taught to do the necessary exercises or stimulation techniques. The Nurse-Home Visitor acts as liaison with the family physician or health agencies in the home area, making regular visits to the home to assure the family's cooperation in faithful participation in the program. She also sets up the specific times of the family's appointments for the child's re-evaluations. She attends the re-evaluations with the family so that she will also

be knowledgeable of changes in the treatment program. During her regular home visits the Nurse-Home Visitor makes necessary arrangements for unscheduled or more frequent visits with the pediatrician or therapist when situations arise that are not anticipated such as illness, regression, or inability of the parents to perform the techniques taught them.

The Nurse-Home Visitor often finds it necessary to determine the family's financial ability to pay for service, thus requiring the Clinic to seek out additional sources of financial assistance such as State Crippled Children's Services, County Societies for Crippled Children and Adults, etc, to offset or underwrite the cost of treatment.

In those cases where placement is desirable, it has been necessary for the Nurse-Home Visitor to provide counseling to the parents, helping them to understand the situation and to accept placement to a more appropriate program such as community classes for the retarded, residential placement if necessary such as foster homes or in state institutions, such as the Columbus State School.

#### VII. What Staff Did We Add? The Nurse-Home Visitor

Because The Lima and Allen County Clinic initiated and planned comprehensive habilitative programs for children both in the Lima and surrounding area that include case finding, diagnosis and evaluation on one hand, to treatment, referral and placement on the other, the addition of a staff person to effectively coordinate and supervise these services was necessary.

During 1967, we added to our staff a half-time professional employee designated as our Nurse-Home Visitor. Long range planning indicates that the program will eventually require a separation of her responsibilities and the employment of two persons: a Nurse-Home Visitor and a Case-Worker. However, at present, we have combined responsibilities of the Home Visitor and Case Worker into one position -- that of a Nurse-Home Visitor. The person to fill the position should be a professional person with a background from one of the para-medical areas, such as child growth and development, occupational or speech therapy, medical social work or nursing. We are extremely fortunate in employing a person who met all of our qualifications in addition to having a cerebral palsied child of her own. She is also a registered nurse and we feel her training as a nurse is helpful in coordinating the medical aspects of the Home Service Program.

Our Nurse-Home Visitor presently has a caseload of 25 patients which includes both the new patients referred into the Home Service Program as well as patients enrolled prior to 1967 but later placed on the program.

The C. P. children in these families can be classified in four ways:

1. Older children attending a regular or special school but coming to the Clinic weekly for therapy.
2. Young children enrolled in the Clinic's Nursery or Kindergarten Program.
3. New referrals just entering our program.
4. Children too severely involved to benefit from an educational program but ineligible for residential placement at this time.



VIII. Summary and Plans for 1968

1. Continue public and professional education programs in the surrounding counties. This will include conducting a Seminar and Workshop in February and a Monitor Training Program in April.
2. More emphasis on case finding and identification of cerebral palsied persons in the Clinic's present service area.
3. Study the possibility of establishing developmental class programs in several of the larger out-lying communities.
4. Attempt to move from a half-time to a full-time Nurse-Home Visitor.

## HOME SERVICE PROGRAM

Presented by  
R. M. Fink, Ph.D., Program Consultant  
UCP of North Carolina, Inc.

The Home Services Program of UCP of North Carolina is approximately four years old. It began with one full-time worker, who also serves as a supervisor. Five half-time workers have been added. The current budget calls for the addition of four more half-time workers. This will provide geographical coverage for the entire state. This is not to say that the quantity of service is sufficient to meet the needs.

In addition to the Home Services Program, U.C.P. of North Carolina operates a day care center and kindergarten in Charlotte and partially supports two other day care centers in Burlington and High Point. Other grants partially support a home-bound teacher program and a sheltered workshop.

### OBJECTIVES

The Home Services Program has the general objective of aiding cerebral palsied children to develop their maximum potentials. Second, it attempts to relieve the families of emotional and physical pressures.

It is not the objective of the program "to assume basic responsibility for all persons with cerebral palsy throughout their lifetimes." We don't believe any agency can assume such a responsibility. Rather, our program attempts to provide certain services to those families which may, for various reasons, need help in finding and using resources and to provide general emotional support to these families.

An additional major objective is to stimulate and guide communities in developing additional resources for these children and adults.

### PROGRAM

The foundations of the program are home visitation, collateral visits (to agencies, etc.) and stimulating the development of community resources. During the past fiscal year, home service workers carried 522 active cases. Seventy-two percent of these cases were referred by local health departments; ten percent by private physicians. The remainder were referred by families, local welfare departments, the National Office, hospitals, friends and a variety of other agencies. These patients were referred from thirty-four of the one hundred counties, thus indicating our need to add workers in certain areas of the State.

Other statistics indicating the quantity of service are:

Number of home visits	1320
Number of collateral visits	1212
Number of patients transported to resources	175
Number of educational programs participated in	312
Number of meetings to help develop community resources	141
Number of other meetings related to U.C.P.	42

Perhaps these figures will take on life by several brief summaries of case records.

John, age nine, was referred by the health department. The worker provided transportation to the orthopedic clinic on several occasions, to a private physician and to a hospital for EEG. Child was referred to a Developmental Evaluation Clinic where worker participated in staffing. Later informed the DEC of seizures in school and medication was increased. Worker called orthopedic clinic's attention to child's hand. A brace was prescribed. During a family emergency arrangements were made with welfare department for food. Persuaded mother to have her prescription for tranquilizers filled. Stimulated mother to apply for residential care for child as recommended by DEC. Transported child to residential center. Refused to make decision for mother regarding bringing child home for Christmas. Child making progress at residential center. Mother moved. Case closed.

Mary, age two, was referred by the health department. Worker helped with appointment and transported to Duke Pediatric Neurology Clinic and for EEG. Arranged for public health nurse to visit regarding the mother's health. Furnished bus tickets to clinics. Checked with Crippled Children's Section regarding delayed payment to Duke. Referred family to public welfare and assistance was received. Instructed mother in pureeing food. Instructed mother regarding handling child so as to permit healing of buttocks. Case open.

June, age eight, was a letter referral from national office. Worker contacted health department clinic and made visit for assessment of situation. Informed family regarding available special education class. Held conference with teacher and arranged for self-help workbooks. Encouraged family to proceed with surgery recommended by Asheville Orthopedic Hospital, which they did. Family was disturbed with results. Checked with hospital and was able to reassure parents. Demonstrated inserts for wheel chair. Forwarded request for physical therapy to health department. Counseled parents regarding need to encourage more independence. Case open.

In studying these and other cases several common threads may be observed. Invariably, general emotional support was needed and provided. Appropriate checks were made with physicians. A wide variety of resources was used. Attention was given to other members of the family and to other family problems. Efforts were made to aid the family to assume its own responsibilities.

#### SOME ISSUES, QUESTIONS OR PROBLEMS

About eighteen months ago, the Board of Directors of U.C.P. of North Carolina felt the need to examine its programs to add to their vitality. The Board is made up of volunteers who are exceedingly busy and who are unable to devote much time to program development, although final decisions rest with the Board. Therefore, a program consultant was employed to advise the Board and to provide program direction. It is the opinion of the Board that this was a wise move and that the program has been clarified and strengthened as a result.

A home service program requires close and effective working relationships with many agencies. These do not always exist or, indeed, may be negative. For example, public health nurses may be most critical of home service workers until they understand the functions of these workers and see that they provide services which are often not possible for the public health nurse to provide, if only because the worker is able to spend more time with a family. An orthopedic hospital may be skeptical of

home service workers who may appear to be "do-gooders" to the highly trained professional. For the past year we have concentrated on improving relationships with various agencies and have seen opposition, doubt or passivity shift to active use of the home service program by many other agencies.

A home service worker must be familiar, in detail with every appropriate local and statewide resource. This requires a constant flow of up-to-date information to and among the workers.

A year ago, U.C.P. was in low visibility in most areas of the State. Deliberate efforts are underway to change this. A directory of services has been sent to all appropriate local and state agencies. An attractive and understandable annual report has been widely distributed. Radio, television and newspaper coverage has been increased. Home service workers have increasingly become involved in related community activities, such as the Association for Retarded Children. A most important step will be the development of local affiliates.

During the past eighteen months, all home service workers have met, at first monthly, now every six weeks, for inservice training sessions. These sessions have covered such topics as:

- Medical supervision
- Nursing supervision
- Goals and limitations of workers' activities
- Relationships with other agencies
- Services of Crippled Children's Section
- Services of Welfare Departments
- Services of Vocational Rehabilitation

With the addition of four new workers we are planning orientation and training programs for these workers.

In general, home service workers are reluctant to terminate their services to a particular family. We have many discussions of the need to recognize specific and limited goals in a particular case. We are in agreement that we should try to help families become more self-reliant. But we are not comfortable in terminating a case. We are able to put it in a reserve file and make, say a yearly check.

We are not sure how to evaluate our programs carefully. We sense improvement and a better organized approach. We recognize increased requests for aid from many agencies, some of which rejected us in the past. We look upon a doubling of our budget by the Board as positive recognition from a group of highly qualified professionals.

On the whole, we feel we are doing a needed job, not being performed by other agencies. We are particularly proud of our influence in the stimulation of additional local resources.



## HOMEMAKER SERVICE PROGRAM

Presented by  
George Dolim, Vice President  
UCP of San Mateo County, California

The constant demands of a handicapped child on a family can make an unbearable situation. Other members of the family are often neglected because of the attention demanded by the handicapped individual. Friction often results in the family. The parents need a respite from the handicapped individual. It is difficult to find a qualified person who is capable of taking care of a cerebral palsied individual. A parent may hesitate to assign this to a teenager or unqualified adult. It is difficult to find anyone willing to care for a cerebral palsied child.

Places built with facilities accessible and useable by the handicapped are limited. A family can only go where a wheelchair or crutch patient can go. The family needs some opportunity to enjoy each other as a normal group, not limited by what they can do with their handicapped family member. Yet the family will only leave their handicapped at home if they are able to obtain competent help.

### I. Initial Organization

A. This problem was recognized by the UCP of San Mateo County as many of the parents have expressed the need for some crisis help. In early 1965 the Parents Advisory Council, a group of fifteen parents, outlined the problem and decided to use a homemaker or residential care. They adopted the National Conference of Homemaker Services 1959 definition of Homemaker Services.

B. Parents made a survey of the desire for homemaker and residential care. Of the 200 families surveyed the results were as follows, in the 115 answers:

Prefer a homemaker service	40
Prefer a residential care	21
No preference	7
Not interested	47

Therefore, the Parent Advisory Council, in February 1965, requested the Board of Directors of the UCPA to explore means of providing this service. The president of UCPA appointed a committee made up of a Day Care Center Administrator, a psychologist, a member of the Women's Auxiliary, and three parents of handicapped children to study the problem and recommend a program. The committee met on April 8, 1965, and discussed the following items:

Receptiveness of UCP families to a homemaker service  
Availability of homemakers  
Methods of employment  
Salary and method of payment.

C. The California State Department of Public Health was contacted to review the project as outlined by the Director. The Superintendent of the Crystal Springs Rehabilitation Center and the Administrator of the San Mateo County Day Care Center were contacted for cooperation in training of the homemakers. Our

county lines were emphasized since there was no homemaker service in San Mateo County and this was the area serviced by the affiliate. The combined efforts of the public and private agency to meet a need in the county for all handicapped children provided a basis for applying for a grant.

- D. The service was publicized by a letter to each parent of cerebral palsied individuals and an announcement to allied groups such as the Children's Health Home for Retarded Children and Adults, the Parents of Retarded Children Association, the California Association for Neurologically Handicapped Children, the Department of Health and Welfare, and the Visiting Nurses.

## II. Present Administration

The UCP of San Mateo County, Inc. received a grant from the California State Department of Public Health, Illness and Aging Unit, Berkeley, California (Standard Agreement No. 558), of \$6,000.00 for the year 1965-66. They received the privilege of training Homemakers at the San Mateo County Day Care Center for Children.

The Parent Advisory Council organized three fund raising events to supplement the money, a candy sale and two Hole-In-One Golf Tournaments.

The Board Committee, made up of the above-mentioned persons, was continued to act in an advisory capacity. The Director was given the job of selecting the homemakers. Both reported to the Board of Directors for approval.

Training Homemakers was begun at the Day Care Center with a week's internship under the direction of the Center's head aide. Reading materials and meetings on topical subjects were sponsored in the community by educational and welfare agencies.

Supervision of the homemakers is done by the case worker, a certified Social Worker, in a conference every other week.

A questionnaire was sent out to parents asking how much they would be willing to pay. Their means average was \$8.00. This was also the amount that the Family Service of San Francisco charged a family of five on a \$6,000.00 a year income, which was the average for our county. The cost of the program is figured at \$24.00 a day per homemaker. Therefore, parents fees pay one-third of the cost of the program. However, \$8.00 is the cost for overnight or 24 hour stay. For an eight-hour period, \$5.00 is charged.

The Public Health Grant is the source of two-thirds of the cost of the operation. Fees are put back into the operating cost. Cost of the program, over the grant money and fees, was paid by the funds raised by the Advisory Council. The UCPA is a United Crusade Agency, but except for general overhead no Crusade money was allocated to the Homemaker Services.

## III. Homemakers

Homemakers were recruited from various sources: Family Service of San Francisco, Catholic Family Service of San Francisco, California State Employment Service, The Department of Health and Welfare, The Day Care Center, the private domestic and nursing employment offices.

Full references were required and checked. Past experience as well as training with the handicapped individual was considered.

The training of the homemaker was at the San Mateo County Day Care Center for Children, which is at 1000 Pohlemus Road, San Mateo, and provides care for severely handicapped children from two to twenty years of age. Visits were made to the School for the Orthopedically Handicapped and the UCPA Nursery School.

The full-time homemaker is paid the salary of the hospital attendant, \$351.00 a month. The part-time or stand-by attendant is paid \$21.00 for a twenty-four hour day and \$14.00 for an eight hour day. Normal rates for regular home-help: \$17.00 and \$24.00.

#### Services Provided by Homemakers

It is required that there be a handicapped person in the home when the homemaker is in attendance. Both parents can not be present and available at the time. The service is for emergency care and respite for the parents. It is limited to a two-week service. If there is a choice, the overnight call has the preference.

Calls are taken from social agencies both public and private, but most calls come from the parents themselves.

#### IV. A. Activity Record and Future Plans

In the period from July 27, 1965 through July 1966, 127 parents were served. There were 315 children cared for during this time.

- B. This amounted to a total of 5,812 hours of homemaker service completed in the year. In no month was only the full-time homemaker busy, and in some months as many as five homemakers were assigned.
- C. It was thought that parents of very small children would be the greatest users of the service. This was not found to be so. Parents of children over ten years of age were predominant. Parents of a fourteen year old cerebral palsied boy, with five other children, had their first night out away from the children in fourteen years. The parents have the responsibility to evaluate the homemaker and the rating of excellent usually is used.
- D. Financial costs have been higher than anticipated as the demand has been greater. It was planned to stay within the grant money and to save the parents' fees for the next year. But the fee money plus monies raised by the parents have gone into the project. The advisory committee is now suggesting a raising of the fee and charging the cost of transportation, which is paid by UCPA, to the parent.

There are plans to expand the number of homemakers. We would like to have a male homemaker for men cerebral palsied individuals. We have had many calls for shorter hours of service. There is a need for a homemaker in every town or city in the county to make transportation less of a problem. There is a need to reach more handicapped groups. Calls have been received for a longer period of service. The lack of funds keep us from making all these improvements. A continuous source of funds is sought.

The objectives of the UCPA Homemaker Services were:

1. To provide homemaker services for families of cerebral palsied individuals in San Mateo County.
2. To provide administration and supervision of the homemaker services.
3. To provide financial support for the continuation of this program.
4. To evaluate homemaker services in the home of a handicapped individual.

The first objective has been widely met. In the period from July 1965 through July 1966, 5,812 hours of homemaker services were given. The following report of months gives an idea of the peak demands:

	<u>No. of Hours</u>
July 23-31, 1965	72 hours
August 1965	416 "
September 1965	312 "
October 1965	840 "
November 1965	448 "
December 1965	552 "
January 1966	160 "
February 1966	386 "
March 1966	464 "
April 1966	392 "
May 1966	624 "
June 1966	450 "
July 1966	<u>696 "</u>
Total	5,812 hours

There were 129 parents affected by the service, and 315 children were cared for by the homemakers. The entire county of San Mateo had been serviced as follows:

	<u>No. of Calls</u>
Belmont	13
Burlingame	23
Daly City	13
Colma	2
Millbrae	3
San Carlos	8
Menlo Park	9
Portola Valley	10
Redwood City	5
San Bruno	4
San Mateo	30
South San Francisco	4
Woodside	1
Pacifica	3
Hillsborough	1

One hundred twenty-nine locations or families were served by a homemaker. Cost of transportation was \$474.22 as paid to the homemakers by the agency. In every



family there was a handicapped child, from 2 1/2 years to 26 years of age. Families were from one child to six children left with the homemaker.

There were 82 single days and 53 overnight stays. The two-day or week-end was the most popular but there were many two-week assignments.

The supervision of the homemaker was done by the case worker, a certified Social Worker, in many telephone conferences and an office conference every other week. The homemaker needed interpretation of the handicapped from a medical and social view point. The problems of the family were discussed with the homemaker. Often the homemaker would see a problem that the social worker was able to explore with the parents on their return. However, most families did not require case work services but just the use of the Homemaker Services for respite. The homemaker felt free to call on the case worker to make suggestions about their daily routines in the home and occasionally had to have authorization to call the doctor for a sick child. At this time, the homemaker and the case worker worked closely together in the parent's absence.

It was hoped that financially the program could continue. The Parent Advisory Council gave three fund raising events during the year. They first gave a Hole-in-One at Emerald Lake Golf Course at which they netted \$500.00. Then in the holidays, they sold candy to net \$1,000.00. They gave a second Hole-in-One in June at which they made \$1,600.00, making a total of \$3,100.00 for the year.

The fees collected were \$2,551.00. The salary cost for the homemakers was \$8,097.25 with an additional \$474.22 for transportation.

The following tabulation shows how closely the Homemaker Services came to being self-sufficient outside of the overhead and administration cost:

Salaries	\$8,097.25
Transportation Cost	474.22
	<u>\$8,571.47</u>
Fees for Service	\$2,551.00
Grant	6,000.00
	<u>\$8,551.00</u>

There were many dramatic times that the homemaker was called into action -- emergency operations, birth of a newborn, mother ill, mother called away because of illness in the family. But the happy parents were those who had the chance to go on a trip away from home with the feeling that an adequate person was at home with the handicapped loved-one. One parent wrote, "Our L's general disposition and well-being in health and temper when we came home leads us to feel that the job had been well done." And another, "Mrs. K. is a wonderful person"; "Mrs. G. is one in a million." "When you no longer need Mrs. G., let me know first."

The evaluation sheet was returned by each parent. In every case the answer was that the homemaker was successful in getting along with the children, especially with the handicapped.

The Homemaker Services has been successful in providing care for those handicapped children whose parents were unable to be with them and providing a way of respite for a number of families. It is reliable service that the community has grown to respect and request.

## DECENTRALIZED DEVELOPMENTAL DAY CARE PROGRAMS

Presented by  
Edwin Minter, Executive Director  
UCP of Greater Kansas City, Missouri

### I. Description of Affiliate

A. Population of service area: One million (1,000,000).

Size: Five (5) counties; Clay, Platte, Jackson in Missouri...Wyandotte, northeast Johnson in Kansas. Area is made up of urban, suburban, industrial and some agriculture.

B. Operating budget: In excess of one hundred fifteen thousand dollars (\$115,000.00) yearly.

Major source of funds: United Campaign of Kansas City, Missouri, United Community Fund and Council of Kansas City, Kansas. Some additional income is derived from membership, clinic fees, contributions, etc.

C. Age of affiliate: Incorporated with the national program in 1951 evolving from a parent council which began in 1947.

D. Staff breakdown: Executive Director, Administrative Assistant, Clerk-typist-receptionist, Social Services Coordinator, five (5) Day Care Directors, five (5) Associate Day Care Directors, one (1) Adult Activity Center Director and (1) Day Care Associate Director-at-Large.

As far back as 1956 the Program Services Committee of this affiliate was concerned with the unmet needs of multiply-handicapped children...particularly those known to be at home and receiving no services because of exclusion from other programs currently offered in our area. A survey conducted by the national organization in 1958 indicated, on the then current incidence figure, that an area of this size and population would include some three thousand (3,000) persons with cerebral palsy. Furthermore, over fourteen hundred (1,400) persons would be in immediate need for some form of professional management of their problems in cerebral palsy. Budget limitations, size of the affiliate service area and many other factors contributed to the final decision to open our first Day Care Center in Independence, Missouri in December 1959. This community seemed to have the greatest incidence of children in the age category that we could program for. A director was hired, the center was opened on Wednesday, Thursday, Friday. Hours were 9:30 A.M. to 2:30 P.M. This schedule was based on the consensus of parents involved. Since then we have opened four (4) additional decentralized Day Care Developmental Programs serving, as strategically located as possible, all five (5) counties that make up our territory.

In 1964 national assisted in a long-term care study for our affiliate. We found that Kansas City had a heavier incidence of severe mental involvement than other cities studied in that general period. In addition, the detected incidence of sensory defects were noted to be higher in our area. These findings seemed to vindicate our judgment in providing services for the more severely involved client.

## II. Decentralization

Budgetary limitations forced the agency to look for and find suitable public facilities on a rent-free basis, located in communities that were accessible to whatever public transportation prevailed or in otherwise accessible locations. Since our major source of funds is the Heart of America United Campaign of Kansas City, it was thought to be politically and economically expedient that a demonstration of local services, subject to a central budget function be clearly defined for the "giving" public.

All centers are currently housed in church property. This seems to be most satisfactory. Because the physical design of most church nursery departments accommodate well the type of client we serve. The philosophy of the church extends itself to considering its contribution to the agency's function to be a part of its ministry to the local community. From the church constituency we draw, for the most part, sufficient numbers of volunteers to assist us in the operation of the centers. Days operated and number of hours were a matter of parent consensus. 9:30 A.M. seemed to be a convenient time in the morning to open because parents are able to get the other children off to school and then prepare and transport our day care client to his program. Meals are served and considered a functional part of the child's training and development while in the center. The 2:30 P.M. dismissal period seems to fit reasonably well because the day care client will be home and properly located before the parents become involved with normal children returning from school.

### A. Staff:

In the early days we developed our own description for the Day Care director's job. We were not sure that we were going to teach so we did not hire teachers. We weren't aware we would be doing a great deal of nursing so we did not hire nurses. The same thing is true with the various therapies. We concluded that our needs would be best met by a person in good physical and emotional health who was flexible enough in approach to be concerned with the ever changing needs of the multiply-handicapped child. We required some exposure or background experience, however. As a result of these minimum requirements this agency is proud to say its day care staff has now become highly trained and has demonstrated abilities to become effective sub-professionals in providing day care programs, program services workshop and literature has done much to bring about knowledge and competence in our field of endeavor. Salary ranges for a three-day work week begin at two hundred dollars (\$200.00) with a current maximum of two hundred sixty-five dollars (\$265.00) monthly.

### B. Fees:

In 1964 the affiliate's Board of Directors examined the cost of day care and concluded that one dollar and twenty-five cents (\$1.25) per day would be the maximum charge on a sliding fee basis for day care. The cost figures have not been reappraised since that date. The fee schedule still remains the same. Incidentally, revenue from the five centers this past year was five thousand dollars (\$5,000.00). The one dollar and twenty-five cents (\$1.25) per day fee is on a per-day-attended basis and is based on parents' ability to pay. Determination



of the amount is done at the time of the initial intake by the Social Services Coordinator. We have found the fee schedule has been most acceptable and has, in fact, made for better programs because of the feeling the parent has in actually participating in the cost of their child's service.

C. The source of clients:

In the early days our clients came to us from families and friends. During the past four or five years the professional community, knowing of our program, refers in increasing numbers. We are proud of the relationship we enjoy with the professional community.

D. Intake:

A client is admitted to the Day Care Program for a trial period as soon as his inoculation record and results of serologicals and tuberculin tests are available. We admit at three (3) years of age and retain clients in the program throughout their sixteenth (16) year. There is some flexibility in this policy. Our centers in Kansas are licensed by the Bureau of Maternal and Child Health and by the Bureau of Licensure in the State of Missouri. Intake is done in the office of the association and conducted by the Coordinator of Social Services. She explains the program, takes the preliminary history, obtains releases for pertinent medical information which will later become a part of the child's permanent record. Then the child and parent are seen by the day care director for additional pertinent information in programming for the child. In the instance where the client is referred to us either from the Birth Defects Center at the University of Kansas or the Multiply-Handicapped Clinic through Children's Mercy Hospital he is admitted without agency screening. We provide a multiphasic screening team which meets four (4) times yearly to see clients who otherwise come to us with insufficient information. The team consists of an orthopedist, physiatrist, ear, nose and throat man and ophthalmologist, social worker, dentist, pediatrician, and lately the services of a pediatric neurologist who has been interested in providing chromatology studies of blood and urine to determine other inborn metabolic disorders.

E. Progress reports:

These are kept on each child throughout the term which runs ten and one half (10 1/2) months of the year. Two years ago the services of a speech consultant were obtained. She visits each center half days weekly. Her function is to work directly with the children, instructing the day care staff in routine exercises and encouraging and training volunteers to participate. She, too, does routine reports on the child's progress. Due to repeated recommendations made by our national services personnel and our own Services Advisory Committee, we have decided now to employ the services of a coordinator for day care services. It will be this individual's responsibility to structure some basic study guides, arranging consultation with other disciplines, relaying information, assisting in evaluations, etc., etc. During the last several years of experience in this program we find more and more developmental aspects become a part of the regular day's activity instead of basic day care or as we like not to say "baby-sitting" services.



#### F. Administration:

The administrative aspects of day care centers as they relate to fiscal matters is the responsibility of the Executive Director. The Executive is also responsible for interpreting board policy and supervision of the day care personnel. Each day care person purchases their own food, supplies and other small items of equipment necessary to operate her respective center. She, likewise, is responsible for recruiting and sustaining adequate volunteers to assist in the operation of the center. We find that the daily operation of the center is affected in direct ratio to the availability of adequate numbers of volunteers. However, time lost due to this aspect is minimal. As soon as the aforementioned coordinator has been hired the agency will then present a team approach in the form of Coordinator of Social Services, Day Care Director, Day Care Coordinator and appropriate Administrative Staff. This team will be used in interpreting screening records, making recommendations for additional service and in assisting parents in locating these available services in the community.

Our experience with volunteers has been extremely gratifying. We feel one of the reasons for this is adequate in-service training direction. We have had excellent cooperation from the national program services staff in furnishing persons for these voluntary orientation sessions which are held, periodically, in the fall of each year.

#### III. Summary

In our opinion it seems feasible to operate by decentralizing facilities in that cost seems to be the prime factor. For example, during the calendar year, 1967, six thousand seven hundred and five (6,705) patient days of day care were attended at a cost of slightly more than twenty-five thousand dollars (\$25,000). I submit to you this is economical programming. Average attendance runs between one hundred (100) and one hundred fifty (150) children daily. This agency does not provide transportation. Volunteers and parents have, so far, been successful in supplying these services. At this writing we have documented four (4) children who are unable to reach our centers due to transportation limitations. Since its inception the day care program has had no waiting list. We are convinced that decentralized services of a supportive nature can not only provide good services but can also lay the ground work for greater community awareness with respect to other unmet client needs. In May of 1967 the agency, for example, embarked upon its first program of adult activity. We have centered this program in a church currently meeting one day a week. Its purpose is to provide social outlet, some individual and group experiences in aid to daily living exercises, etc., etc. Recently, the Executive Committee voted to increase this to a two-day-a-week program with the provision of transportation services for approximately fourteen (14) to twenty (20) clients. The adult client in this program becomes, in effect, an advisor to our Services Committee. We hope to establish long-term concepts of programming of this type in order to provide a continuum of care for those youngsters who "graduate" from our day care centers. I hope to report, positively, on this project at some future hearing date.

PLANS FOR A RESIDENTIAL CARE FACILITY  
WITH COLLATERAL PROGRAMMING

Presented by  
Sidney Marks, Ph.D, Executive Director  
UCP of Nassau County, Inc., New York

I. The Scope Of The Need

With an aging Cerebral Palsy population, with the pressures of public facilities being unavailable or less available, with the increasing strain which is then placed upon the person with the disorder and his family, the community must help shoulder these burdens, provide what is needed for residential care, and find the means to bring a brighter future for our Cerebral Palsied.

II. The Proposal

We propose the construction of a Residential Care facility on our premises at Roosevelt, Long Island, which will utilize supportive services-- medical treatment, training and education--of our Rehabilitation and Treatment Center. The Residence will offer the occupants living facilities which must not be institutional in character. It will offer the occupants social and recreational facilities. It will enable the handicapped to manage his or her day-to-day life as an independent individual. He will have a job either at the UCP Center Workshop or in the Community, a home, a social life of his own, a sense of security, care and compatible companionship.

III. The Nature Of The Facility

The Residential Care facility will be the first of a series of units. It will be basically a place of residence for from 15 to 30 multi-handicapped men and women adults who may or may not be able to participate in Center or community jobs or programs during the working day.

The facility will not be adjacent to or part of the Center. Staff employed will be counselors or house parents, rather than parental substitutes. The Cerebral Palsy Center as the operating agency will have administrative, supervisory and service responsibility for the Residential Care facility.

The facility will use Center and community resources and activities. Significantly, its housing and architecture should be undistinguishable from nearby homes.

A sub-committee on facilities of our Residential Care Committee has been engaged in the inspection of existing facilities, all of which deal with the mentally retarded. Many of these facilities have physical characteristics which can be adapted or modified to fit our situation.

A representative type of facility which bears presentation is that which has been just constructed at the Seaside Regional Center in Waterford, Connecticut. It is a 30 bed residential cottage, containing residential facilities for thirty residents with office space for personnel involved. (We would require living quarters for house parents or other care personnel, as well as office space).

The location of the building (as in our situation) has been removed from the center of the institution. The design of this building (as in our situation) makes possible great flexibility in terms of those who will be living there. The building is designed to accommodate physically handicapped, ambulatory or otherwise, so that they can be programmed for on the basis of abilities rather than being housed in non-ambulatory wards with far less capable individuals.

In this Waterford structure there are thirty beds in two wings of fifteen beds each. Each wing has seven two-bed bedrooms and one one-bed bedroom. One wing can be used for male and one for female residents. Any number of physically handicapped, including non-ambulatory residents may be included in these groupings. Each wing contains one common room which is used as a casual sitting room. Toilet and bath facilities for fifteen residents are also provided in each wing. (We would prefer individual rather than community bath and toilet facilities.)

Each wing is connected to a center section which contains living room, dining room, kitchen, office, visiting room, front and rear entrance foyers, clean and soiled linen storage and janitor closets. It has a basement area for general storage and for laundry and recreation rooms. A patio and barbecue area is connected with the dining and living room area.

Ramps are provided in the rear of the building with access to the residence as well as to the basement area. The cottage is landscaped. Parking facilities are provided. A delivery road is provided.

The bedrooms of the Connecticut installation are far too small for our needs and Community toileting, while less expensive, defeats the whole conception of privacy and individual living. No provision is made for cooking on the premises although a snack kitchen is provided. No provision is made for living quarters or staff quarters for supervisory or care personnel on the premises.

Nevertheless, it is a facility which bears study and consideration as it embodies many of our ideas and projections for our handicapped.

#### IV. Estimated Cost Of The Residential Care Facility

The facility which is currently proposed will meet only minimum needs. The Connecticut facility which is about 7,650 square feet and is inadequately built for our needs, both in size of rooms, toilet, bath and kitchen facilities, recreational facilities--in general, inadequate living room, required approximately \$300,000. Mr. Aaron Kushner, Chairman of our Sub-Committee and a builder, estimated the costs of an adequate Residential Care facility at \$500,000. This would include equipment. Mr. Arnold Rinaldi, a local architect of reputation, who has acted as consultant for us on a number of projects, rendered an advisory opinion which indicated that the \$500,000 was a reasonable estimate.

#### V. What the Residential Care Facility Will Do

The Residential Care facility will provide a living situation for men and women adults including breakfast and dinner. It is a permanent home for a handicapped person to take care of his personal needs and to participate in a daytime program such as competitive employment, sheltered employment, sheltered workshop, a vocational program or educational program.

It will also, to the extent possible, be a short-term care Center to provide accommodations and facilities for the multi-handicapped for not more than 90 days for situations of common disaster, parent or family illness or for temporary care during the absence of parents or family.

The Residential Care Residence will not be just a place in which to live. It will be a self-governing community--a total approach to life. An adult setting will encourage and sustain maximum independence both vocationally and socially. It will be an adult setting in which freedom will go hand-in-hand with the guidance and care needed by our handicapped to get over the hurdles and hazards that would ordinarily leave him completely to his own devices. In short, our contemplated residence places the handicapped "on his own" but never leaves him stranded. He has a place to live, a nearby place to work, and an accessible place which will take care of his medical needs.



## STATE-SUPPORTED RESIDENTIAL AND OUTPATIENT THERAPY PROGRAM

Presented by  
Harper Orth, Administrative Director  
Oklahoma C.P. Center  
Norman, Oklahoma

The State of Oklahoma has long been interested in services to the cerebral palsied. In 1948, the Oklahoma State Legislature took over the Cerebral Palsy Treatment Center located in Norman, Oklahoma that had been originated by the "40 and 8" of the American Legion.

This is a state residential therapy program providing both in-patient and out-patient services for those who are under twenty-one years of age, residents of the State of Oklahoma, diagnosed as cerebral palsied, and considered trainable. In addition to those who are eligible for in-patient services at the Center, the program provides services for those who are not considered trainable but have need of braces, chairs, standing tables, equipment of various types, and home, medical and dental programs. To my knowledge, this is the first state supported in-patient therapy school built for and operated for only the cerebral palsied.

Since its inception, the program has progressed in providing services. The residential center at Norman offers 48 beds for those in-patients who are recommended for intensive therapy programs at the Center. The average length of stay last year per admission was 111 days. The out-patient services have increased tremendously in the last few years, quadrupling in the last five. This program offers Physical Therapy, Occupational Therapy, Speech Therapy, Psychological testing and counselling, Special Education, Dietary, Nursing, Medical and Dental services for those meeting the requirements for admission. An audit just completed two weeks ago showed that last year the Center had a percentage of occupancy of 90.84% for the past fiscal year. This is, of course, with the children who are ill going home, and in most cases, children going home over the weekend.

Additional Hill-Burton state funds have recently been made available to expand this program by the addition of 24 extra beds, relocation of the laundry, additional recreational facilities, and the building of another additional school room. The swimming pool on the grounds is now in the process of being rebuilt, and it is hopeful that by next fall this will be in an enclosed area where it can be used the year around. Students from the various state schools, particularly in the para-medical fields such as Physical Therapy, Occupational Therapy, and Speech Therapy affiliate at the Center. Also, Physical Therapy students from Baylor in Dallas, Texas, are sent to the Center for training to work with cerebral palsied persons.

In 1962-63 The United Cerebral Palsy Association made a survey of the problems of the cerebral palsied of Oklahoma. Much of that which was recommended has been accomplished as far as the services at the Oklahoma Cerebral Palsy Center are concerned, and we are continually working to improve the areas of service that were in this report. In the five year plan of operations that was sent to various members of the panel, the State of Oklahoma has all the problems associated with the problems of those in other areas. The early identification of infants and very young children with cerebral dysfunctions still needs much improvement, although much has been accomplished. For instance, in 1952 the average age of occupancy of those children who were in-patients at the Oklahoma Cerebral Palsy Center was eleven years and ten months; in 1957, the average age was eight years and four

months. In 1967, the average age had decreased to five years and two months, primarily, because of the earlier diagnosis of cerebral palsy and the need for early programs for these children. The United Cerebral Palsy Association is doing much to help educate the medical profession as well as para-medical and lay people as to the multiplicity of problems of the cerebral palsied and the facilities available to those who have need of assistance.

A NEW ROLE FOR UNITED CEREBRAL PALSY  
IN PREVENTION AND EARLY CARE

Presented by  
Helen Wortis, M.S., Director  
Studies of Urban Children  
League School for Disturbed Children, Brooklyn, N.Y.

United Cerebral Palsy now has an opportunity to give leadership to the whole country in a program of vital importance.

In his last report on the State of the Union, President Johnson mentioned that the United States ranks fifteenth in the world in infant death rate. These are the figures from which he quoted:

Infant Mortality, Selected Countries, 1964<sup>(1)</sup>

Sweden .....	14.2	England and Wales .....	19.9
Netherlands ...	14.8	Japan.....	20.4
Norway .....	16.4	Czechoslovakia.....	21.2
Finland .....	17.0	Ukranian SSR .....	22.0
Iceland .....	17.7	France .....	23.3
Denmark .....	18.7	China (Taiwan) .....	23.9
Switzerland....	19.0	Scotland .....	24.0
New Zealand....	19.1	Canada .....	24.7
Australia.....	19.1	United States .....	24.8

These are sobering figures since "infant mortality has long been considered an index of the level of health of a community. High rates are associated with low socioeconomic conditions, problems of environmental health, limited medical facilities and resources, and concomitant low levels of prenatal and obstetric care"<sup>(2)</sup>

President Johnson might have reminded us that the major cause of neo-natal death is low birth weight, more popularly called premature birth. In 1960 children with low birth weight represented only 7.7 of all new born infants, but deaths among these children accounted for two-thirds of the total number of neo natal deaths<sup>(3)</sup>. It is important to realize, moreover, that the proportion of low birthweight infants is increasing. In 1950 our national statistics showed 7.6% born with a birth weight of 2500 grams or less. In 1963 the rate was 8.2%. "Unless some major changes in the infant mortality rates take place in the United States the situation in respect to other countries will only worsen."<sup>(2)</sup>

It is well established that low birthweight is usually a disease of poverty<sup>(4)</sup>. The World Health Organization Expert Committee on Maternal and Child Health has brought together the evidence to show that a high rate of premature births is associated with poor prenatal care, poor nutrition and the stressful conditions of life associated with poverty. These conditions affect the growth of the fetus at all stages of gestation. Their report states:

"The unfavorable conditions associated with low birth weight will vary in degree and substance throughout the world but will include a variety of unfavorable factors which may affect adversely the health and general efficiency of the mother, including malnutrition, infections, fatigue, and overwork,

bad housing, inadequate educational and health services. There is also evidence that these conditions unfortunately are of a type that do not occur singly."<sup>(5)</sup>

Out of wedlock infants, particularly those born to girls under 19 years of age, are very likely to be underweight.

The prevention of low birth weight and the diseases consequent to it is therefore essentially a question of the improvement of social facilities. To the degree that low birth weight can be prevented by improving social conditions, so can the handicaps associated with low birth weight be prevented.<sup>(6)</sup>

In the United States, as in other countries, the rate of prematurity is highest among infants whose mothers are poorest. Women in the lowest income group, who have the poorest education, and live in the poorest housing, are the ones most likely to give birth to low weight infants. In 1961 the percentage of premature births was 7.5 in the Chicago census tracts where income was highest and 15% in the tracts where income was lowest. Comparable percentages in New York City were 6.2 for the highest income groups and 16.5 for the lowest.<sup>(7)</sup>

Women who receive little or no prenatal care are more likely to have light weight babies than women who have more adequate care. In the United States, Negro, Mexican and Indian women give birth to a much higher proportion of low-weight infants than white women. Our high prematurity rates are primarily due to the increasing proportion of low weight infants born to our non-white population.<sup>(3)</sup>

Percent of live births by birth weight and color  
United States 1950 and 1960

Year	Total 2500 grams or less	White 2500 grams or less	Non-white 2500 grams or less
1950	7.6%	7.2%	10.4%
1960	7.7%	6.8%	12.8%

Last, but perhaps most important, is the relation between maternal nutrition and the infant's birth weight. Many studies have shown a close relationship between maternal nutrition and the baby's birth weight. It is suggested that the mother's poor health and nutrition depress fetal growth or may result in the premature onset of labor. Indeed, experimenters have increased the anticipated birth weights of a group of newborns by bringing pregnant women into a maternity home several weeks before delivery and providing increased nutrition and rest.<sup>(8)</sup>

When low-weight babies survive, a large proportion have cerebral defect or mental retardation. Even when no obvious defect is apparent, it has been shown that the IQs of these children are lower than those of their siblings.<sup>(6)</sup>

What must be done to remedy this situation? Obviously, something already has been done in this country to reduce the infant mortality rates from the much higher levels which prevailed at the beginning of this century. Much however remains to be done. If we turn to the countries which have reduced their rates below ours, we find them quite explicit in naming the particular measures which,



in the opinion of their own experts, are responsible for their superior public health statistics. In an International Conference on the Perinatal and Infant Mortality Problem of the United States, held in 1965 under the sponsorship of the U.S. Department of Health, Education and Welfare, the representative from Norway cited specific social reforms in her own country which had reduced their infant death rates. These included: "In 1911, an introduction of national sickness insurance, in 1936 the provision for leave of absence from work of pregnant women before and after delivery, and in 1946 special allowance for all breadwinners supporting more than one child."<sup>(2)</sup>

It is my opinion that the American people are unaware of the wide gap between our concern for every child and the actual poor services as reflected in our infant health statistics. I propose that UCP be in the forefront of a national campaign to bring these facts to the consciousness of every citizen, and that we launch a movement to educate the people into a knowledge of how to reduce our low birth weight and infant mortality rates. I suggest that we focus on a program to prevent cerebral palsy and mental retardation by reducing the national rate of low birth weight infants to levels comparable to the lowest in the world, within ten years. This is a commendable method of international competition. Such a campaign would have to be planned cooperatively with government and voluntary organizations, with leaders in the health field and in the field of social action. National Educational and legislative programs would have to be designed. Communities would be helped to investigate their local situations and to improve them.

Examples of UCP activity in such a program would be:

A. National UCPA

Prepare and distribute educational and publicity material in women's magazines, national publications; distribute posters and leaflets. Launch a national campaign to improve nutrition of children and women of child-bearing age. Introduce legislation and secure support for a national program of free school lunches designed to provide the basic minimal nutritional requirement to every child. Support and broaden federal programs for improved maternal and child health care.

B. Local UCP Affiliates

Starting with the affiliates, help communities review their own public health statistics in order to bring into public view the areas with the highest infant death rate and low birth weights. Help those authorities develop preventive programs in cooperation with local government, health and anti-poverty authorities. Investigate local provisions for the care of young unmarried mothers, with a particular concern for shelter care. Review the adequacy of local health services in relation to the needs of working women and women with small children at home.

The success of a ten year program would be highly visible to the entire community. A well publicized and successful campaign would be of benefit to every citizen and would reduce the number of cerebral palsied children born every year. It would bring UCP to the fore as a leader among the voluntary health agencies.

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PRE--PRE--SCHOOL PROGRAM  
(BABY STIMULATION GROUP)

Presented by  
John Lynch, Executive Director  
UCP of Greater Louisville, Kentucky

Our occupational and speech therapists found that the regular therapy period of one-half hour did not provide the best setting for maximum learning. Therefore, they decided to combine their time and group the children in small numbers to see if they would stimulate one another. Their initial efforts produced results, and they decided to continue the plan. The occupational therapist and the speech therapist work together in the group; and, in addition, two volunteers assist during the whole session.

This pre-pre-school activity takes place one morning each week and is divided into three periods of one hour for each of three groups. The children, ranging in age from 12 months to 3 years, are grouped according to social maturity rather than age.

An overall stimulation program is provided. The time is pretty equally divided among the problems worked on, namely: receptive language, auditory stimulation, vegetative patterns, articulator mobility, socialization, and Rood therapy. The therapists found that close proximity of children with freedom on a mat encouraged more interaction and free babbling.

The period usually starts with play therapy. All toys are kept alike -- though different in color -- so that every child uses the same kind of toy at one time. A tape recorder, with short, simple melodies and familiar sounds, is used to stimulate babbling. Short nursery songs are used upon occasion.

Drinking through a straw and chewing are practiced. The Rood method is used to stimulate chewing and swallowing and to help control drooling. In the beginning each parent is given a demonstration of this method on his child. The parent is instructed to use the same method also at home at least twice a day about 15 minutes before feeding. Each child has his bib on when he arrives. He brings with him his own individual sack, bearing his initials and containing straw, two brushes, baby spoon, and pacifier. If a child cannot suck through a straw, his pacifier is attached to the straw in order to stimulate straw-drinking.

The parent is requested to remain in the reception hall during the group period. If the child becomes fussy, he is taken to his parent. He may, however, return to the group, if and when he becomes quiet. If the child needs changing, the parent must attend to that matter.

On the same morning, physical therapy -- if scheduled -- is given either before or after the session. Last year, when the group activity was first started, children were removed from the group for physical therapy; but such an arrangement was unsatisfactory, and the present plan is working out much better.

Results of last year's training are evident this year in the nursery school. Those who entered nursery school this year adjusted beautifully at the outset. Formerly, many children entering nursery school for the first time cried for

varying periods before adjusting to group activity. Pre-pre-nursery school prepared the children for the transition to nursery school. When they found themselves in nursery school with children they had previously known in the other group, they did not experience difficulty in adjusting to other children or to a new place. The therapists and nursery school teacher are enthusiastic about the possibilities of the program in encouraging early learning and future adjustment to nursery school.



## PRE-NURSERY SCHOOLS FOR PHYSICALLY HANDICAPPED CHILDREN

Presented by  
Margaret H. Jones, M.D., Professor of Pediatrics  
University of California, Los Angeles, California

What are the problems facing parents and physicians and educators and psychologists and social workers in relation to the management of very young children with delayed or abnormal physical development? How are these problems different from problems in the "normal" infant and young child?

Problems presented by parents include:

1. Lack of expected response of infants to parental attention -- as lack of fixation and following with eyes, little attempt to bring head forward when pulled to sitting, little reach and grasp, listlessness or irritability.
2. Difficulty in feeding -- slow, noisy, much "gas", excess salivation.
3. Difficulty in sleeping.

The Physician's Dilemma:

Knowing the wide variation in normal growth and development, the physician must consider whether one or more of the problems presented by the individual child is related to non-progressive or progressive upper motor neurone or other abnormality, is a specific therapy available, is the delay due in whole or in part to environment? This is not a simple or easy diagnosis.

Also we do not yet know to what extent early training procedures of any type can influence the long term outcome in those infants with non-progressive upper motor neurone abnormality present from birth or early infancy. However, it is known that sensory deprivation is a factor in delayed development and common sense dictates that the lack of normal experience not only from visual, but also auditory, tactile, and kinesthetic input will deter normal development in the physically handicapped as well as the physically normal infant and young child. In addition, the child with a physical handicap tends, very naturally and in many ways, to be unusually close to the mother or conversely to be a source of irritation and worry to her rather than providing her the pleasurable experience anticipated with the young infant.

How can the pre-nursery school assist in evaluation and training of such children? Experience over the past decade or more with small units for such children who are under three years of age suggest the benefits to fall into the following categories:

1. those to the parents
2. those to the child
3. those to the physician and other professional staff.

## Benefits to the Parents

By the age of 1 1/2 years the normal child is beginning or has begun to explore physically the world about him. The child with motor and usually one or more sensory deficits, has difficulty in getting away, difficulty in achieving his goals and may well become frustrated. There is nothing that spurs any of us to further endeavor like success and this is true from earliest infancy. How does the parent assist the child to be successful in his explorations if he has a physical handicap? A unit designed to provide a variety of furniture and equipment plus a staff who can evaluate what is best suited to the individual child can help to change a physically handicapped, frustrated, young child from a fussy, irritable or listless one into a more normal, inquisitive "toddler" even though his "toddlings" itself is delayed.

The importance of visual perception has been so emphasized in recent years that we are apt to overlook the fact that the young child is confronted with more problems than just that of visual perception. He has to develop more meaningful auditory perception, to integrate with both tactile and kinesthetic input, to attend or pay attention long enough to "learn." We often speak of the short attention span of those with "brain damage." Studies in older children have shown that special teaching techniques can improve both behavior and learning in many such children. When should this type of "teaching" begin? The parent is the most important "teacher" for the young infant, but can we expect the parent to "come equipped" with special knowledge of ways to provide satisfactory learning experience for the "toddler" who does not "toddle" and who may have multiple sensory impairment and who does not fit into the usual furniture our culture offers for sale?

The pre-nursery can help the parent in understanding the child's problems, in working out ways to overcome them. In addition, the association with other parents with comparable problems is not only supportive but helpful. Each parent, in order to "teach" their own pre-school child must first understand and second be able to accept the child as he is in order to help him grow.

As the children in our pre-nurseries have gone on at 3 years usually to the public schools for physically handicapped, the school personnel have repeatedly commented that the parents as well as the children are much more ready for the school program.

## Benefits for the Child

As the child comes into the nursery, at first just for a short visit with his mother, gradually he can be seen to watch with greater interest, the other children and the toys. As he becomes accustomed to the situation he can leave his mother's arms and be closer to the activities in the room. He can learn that there are other adults who love him, not just mother. He can learn to let them help him. He can learn that there are things that he can really do - not just fail when he tries. Little by little he begins to try more. Attention span can be seen to increase, abilities to grow. He can become accustomed to the most appropriate equipment, can be trained in eating and can learn to sleep in the best position - all this because he is able to accept change, to allow others to help him. In turn the parents can be more confident and more successful in their teaching and training at home.

There is much more than the physical, occupational and speech therapy involved in the early training of the child with delayed development.

#### Benefits for the Professional Staff

For the physicians, a young child with delayed development may be quite difficult to evaluate in the usual examining room. Observation of his behavior, his ability to move about and to use his hands may be much more informative or may add appreciably to this type of examination. This is particularly true if the "toddler" is either very irritable or very listless.

Also, and importantly, in the pre-nursery situation, clinic research is possible in respect to training procedures. For example, we have been studying two techniques applicable to the child under three years of age, techniques that are concerned with multi-sensory input, attention and interpersonal relations. One is the sensory story. This is a simple short story, told by the teacher in a one to one relationship and involving objects presented singly and in context. Another is the confined space study. In this project, children are invited into a small "playhouse." The dimensions are determined by the number of occupants allowing 2 1/2 sq. ft. for each person in the area, i.e. for ten people the dimensions would be 5 x 5 feet. Only a few soft toys or scarves are allowed. Children are watched by staff but are left to interact with one another in any way that close proximity suggests unless their activities are harmful.

#### Staff and Facilities Needed

Experience has shown that a twelve child unit is optimal for this age group of 1 1/2 to 3 years. Staff consists of a teacher full-time, preferably one with training in nursery school education, an assistant teacher, at least one trained volunteer, one parent who is receiving direct guidance from the nursery school teacher. Occupational, physical, and speech therapists part-time working with the nursery school group are essential. Consultants include pediatricians (preferably pediatric neurologists), orthopedist, physiatrist, ophthalmologist, otorhinolaryngologist, psychologist, psychiatrist, dentist, social workers.

The facility should be a classroom, size probably, at least, 20 X 30 feet with an adjacent toilet used exclusively by the nursery school children in which toilet training is given. An outside play area should be set up to promote activity, but should have a feeling of space, uneven ground, and freedom for the child to choose his own activity.

#### Program

In our experience for many children five days a week is optimal and usually includes lunch and nap. However, each child presents special problems and needs to be considered individually and re-evaluated every three months at least to develop the best plan for him. Some may come three times a week for part or full days, some more, some less.

Recently we have found that one therapist (occupational or physical) assigned to work with each child and his parent and with the teaching staff regarding this child has been more effective than having each child referred for both physical and occupational therapy. Our entire staff evaluates them

first and together makes recommendations. Each week, for one hour, the parent works with the therapist assigned to that child in order to review the child's therapy program and plan the parent's daily part in it. The therapists work in the same room, a room directly opening into the classroom. Therapists also enter the classroom to participate in developing activity, sleeping and feeding programs suited to the child's individual needs.

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SERVICES TO PARENTS OF PRE-SCHOOL CHILDREN

Presented by  
Dolores M. Goidel, Director of Children's Services  
UCP of Queens, New York

United Cerebral Palsy of Queens received a grant from a private organization for program expansion of their infant services. Main objectives of this service are to assist parents to understand, accept, plan together and work with the limitations of their children (severely involved, aged 18 months to 3 1/2 years). Also, to learn improved means of coping with problems developing out of their children's disabilities. Simultaneously, the children receive early stimulation leading toward their awareness and interest for their environment, independence in A.D.L., social adjustment and sensory exploration.

Family problems have been compounded too long because most facilities have traditionally offered one-sided, or at most two-sided, services. There has been little evidence of longitudinal programming which has contributed to the parents shopping around. Children who have problems at school age and adulthood have problems at the infant, toddler levels. Families too frequently are being told, "Come back when the child is more independent or when he is toilet trained"; or "Go find some school program somewhere." This advice is worse than no advice at all. The child's needs are now. Facilities should be designed to meet the family and the child's needs from the beginning. There has been too much delay in programming for the early age. Many youngsters have spent too many years without stimulation, flat on their backs.

The experimental program constructed at UCP of Queens tries to meet the total needs of the family. Twenty mothers and their children attend half-day sessions on Tuesday or Wednesday and Friday. Typically, parents participate in therapeutically-oriented small groups on Tuesday or Wednesday and in larger education groups on Friday. In addition, the Friday meetings enable parents to participate in the UCP of Queens school program at levels consistent with their emotional readiness to do so. Fathers are scheduled for two evening discussion groups each month and are encouraged to verbalize their role and problems in reference to their youngster. Six student teachers (advanced students in professional education programs at Teacher's College, Columbia University and Queens College of the City University of New York) have been trained to work with the children while the parents are receiving Project services. Under professional supervision, these students assist the children to understand the world around them, to develop self-care abilities, socialization and sensory perception. We have a ratio of one student teacher to three or four children. Structure is built into the program so that the children will gain a feeling of security and consistency of handling. Much of the activity is handled in groups. We had little precedent to know whether we would accomplish this type of interaction at the children's age of 18 months and two years. We did not know whether we could successfully get the children around a table for even a brief time. They have already started to understand that group direction

and interaction is more fun than idling about. Let me stress at this time, that we do not feel that these little ones should only have group experiences. We feel that both group and individual work are necessary. The role of the group process has been supportive and has helped these little ones to be better prepared for individual therapeutic work.

The professional staff consists of a Project Coordinator, a social worker, an educational therapist, a public health nurse, a consulting physician, and student aides. In our program, the individual work is carried out by our occupational therapist. Child care activities initiated at the Center are carried out in the home by the parents with the support of the Project Public Health Nurse. Meetings are conducted for the student teachers at the conclusion of each session to provide supervision and to improve their performance.

Some of the Outcomes of the Program to Date are as Follows:

1. Parents have responded almost 100% to the program and its provisions by continued attendance and becoming involved in the child's progress and cooperating in any recommendations made concerning their youngster.
2. The twenty parents were found to have wide-ranging concerns, previously not communicated to others. These concerns related not only to the care of their children but also to unresolved personal and family tensions which restricted their effectiveness with their youngsters. Within a brief period of time, these parents acquired sufficient security to discuss these problems with project staff members and with their therapeutic groups. Some of the parents have expressed a sense of relief from some of their most pressing concerns about their families and themselves.
3. At the time of entry into this program, most of the mothers felt socially isolated. The demands made upon them by their disabled children and by other household responsibilities had reduced their social interaction. Almost all expressed a sense of despair in being "alone" with the problems of caring for their youngsters. Withdrawal of many fathers from the home situation, refusal of other siblings to go to school and severe depression of either parent was seen. The planned interaction of parents with each other in the program has been effective in giving mothers and fathers a renewed sense of identification with others in the community and an appreciation of the problems of others in coping with their disabled children. Some of the mothers help each other outside of the center in their day-to-day problems, even though they had had no contacts with each other previous to entry into the Project.
4. Home Visits conducted by a Public Health Nurse have been beneficial in order to effect a carry-over of suggested activities into the home. This service provides a supportive reinforcement for the mother in her work with her child.
5. The staff considers at least fifteen of the twenty children as potentially suitable for subsequent special and regular school programs. Five are doubtful. Of the latter, two are also severely emotionally involved.

Services will be sought for these two so that proper professional intervention will occur as early as possible in their development. Additional observations of all the children will be made as time goes on so that selective school and other placements can be made. Since we are not a treatment agency, in all instances liaison is being maintained with the respective children's hospital facilities.

6. Progress also has been noted in the management of solid foods, toilet training, independence, and the children's readiness to relate to adults other than their mothers.
7. Improvement can be demonstrated for every infant in at least one developmental area, with due allowance for the maturation process.
8. Interpersonal relationships with resulting motivation to communicate have developed far beyond expectations for this age group. They support, help and teach one another within the group setting.
9. The children have begun to show the results of group structure: an acceptance of routines, enjoyment of structured tasks, more constructive use of energy, building up of higher frustration tolerance, ability to wait and share, and fewer tantrums.
10. Parents and siblings have come to a greater understanding and acceptance of the child in the home.

In conclusion, when a child is born with a defect, he is also born into a family. In his early helplessness and dependence, as well as in his later achievements and failures, that family can be his greatest support or his greatest weakness. Our task is to design programs that will assure this child a happy and responsible family and to help the family in developing a child who will someday grow to adulthood and function within the limits of his disability and take his place as a member of society.

NURSERY PROGRAM

Presented by

Peter Halpin, Executive Director  
UCP of Tampa, Florida

The nursery program that has now been in operation at UCP of Tampa since 1962 was initiated because of the increasing number of children under the age of five being referred for services. Prior to that period and since 1959 a similar program for children ages 6-8 was conducted for the cerebral palsied who were not qualified by training or experience for public school.

In 1962 with a combination of therapies, physical therapy, speech and occupational therapy, it soon became obvious that beginning with the CP child about age 15 months much more could be accomplished. Then the child at age 6-8 had the benefit of all that could be offered to qualify for public school admission at age 6.

The gradual shift in age and program emphasis by UCP may have conditioned the growth and expansion of the exceptional child education program of the Hillsborough County Exceptional Child Education Program than all other handicapping conditions combined. Records indicate that the CP child was able to remain for a broader educational experience than any of the other handicapping conditions.

In 1964 with an increasing number of children being referred under the age of three years, it was decided to split the Nursery program into two sections. The morning group was classed as the developmental section, ages 15 months to 3 years. The afternoon group consisted of pre-school ages 4 to 6 years. Both morning and afternoon sections of the Nursery program were developed along psychological guidelines (psychological consultant) with the thought of providing all the ingredients of a standard or normal nursery program not available to the CP pre-school child.

The greatest asset of the combined nursery program is that it brings children together in a group-sharing experience where the needs or problems of the child are observed in many different facets of activity (3 hours per day) under supervision and away from an over-protective atmosphere or possibly limited home experience.

There is apparently a greater motivational atmosphere where the child can observe his peers in less threatening activity than possibly would be true on individual or one-to-one basis. There is a greater incidence of behavior activity particularly in the morning group when attendance is full, in contrast to the periods when many of the children are absent.

It is certain that the toddlers enjoy large groups (arbitrarily 8 or more) where they can go along as part of the activity rather than being conscious of themselves as the activity. There is apparently a great deal more enjoyment if not benefit derived from this type of group association.



The use of groups enables certain speech and physical therapy techniques to be carried over in the nursery program, as well as other routines (ADL) according to the needs of the individual child or as time permits. Through the use of groups there is an opportunity for the child to develop self-assurance and confidence which is probably reinforced by the child's ability to perceive not particularly the accomplishments of other children, but their enthusiastic participation.

In general it would appear that the nursery as well as being an important phase of training, socialization and education, is an excellent vehicle for the carrying-through of all phases of a program of physical therapy, speech and occupational therapy.

Basic to the growth of the program was a vigorous program of public education in conjunction with the acquisition of a new treatment center in 1965. In two years our program grew from 18 children receiving daily services in 1964 to 51 in 1967, with an increase of 5,000 to 10,000 units of service for the same period. The success of this program was the availability of specialized services to children at the period of optimum advantage, 15 months to 6 years.

Exceptional Education Division of the Hillsborough County School System has commented that UCP of Tampa in its Nursery program saves them 5 years time in working with the handicapped CP child. Since 1962 five to seven children each year are accepted for admission to the Hillsborough County public school system.

With the growth of our local program on the pre-school level insurmountable problems occurred (financing and lack of adequate help). However, as a result of efforts by our professional advisory committee, in November, 1967 Exceptional Child Education created a pre-school program and two of our pre-school children, age five, have been accepted for admission.

Currently UCP of Tampa has an enrollment of 34 children in the nursery program. All children are admitted based on an individual therapy evaluation (speech, physical, OT and Nursery) and a combined examination of the therapists with our medical and psychological consultants. Each child is reviewed every 3 months and, in 1967, 163 children were under program supervision. In December, 1967, 38 of these cases were closed out as a result of discharge, institutionalization, moved out of the County or transferred to other community services.

Four classifications\*

1. Moved	10
2. Institutionalized	8
3. Transferred to another community service	6
4. Non-attendance	7
5. Discharged	7
	<u>38</u>

\*The four classifications do not include children admitted to the school who require UCP supervision. (Six were admitted in 9/67)

In a study of 41 children receiving one or more daily services of the

Center in 1967 --

Five were classified as profoundly involved, either by physical limitation and/or mental retardation.

Seven were severely involved.

Twelve were moderate.

Seventeen were minimal.

Twenty-nine of the children have excellent potential and twelve have limited potential. Not all referrals are accepted. If a child is functioning at a normal range of potential, he is not accepted. Consequently, if a child cannot benefit from the program he is not admitted.

The modest success of the local UCP nursery program is attributable to many factors and most important of these is the concept of a well-rounded program rather than a collection of individual services. It is not important who provides what services or who pays for it, but rather that the services are provided in a continuum where all focus on the total problem. UCP of Tampa has been fortunate in being able to provide services on this collective basis where all of the therapists can share their professional insights.

It is difficult to continually reinforce the concept of a total program with eight staff, four consultants and two youth corps workers. However, it is a very necessary phase of a successful nursery program.

SMALL BUSINESS ENTERPRISES PROGRAM

Presented by

Leo Meyer & William Dippel  
Vocational Services  
UCP of New York City

"Small Business Enterprises" has been conducted since 1966 with the initial purpose of exploring the potential and providing training for the cerebral palsied in small retail operations. The original training vehicle was a vending stand located in one building of a six-building middle-income cooperative housing project in the Bronx, New York, known as Concourse Village. The space for the vending stand was arranged for, rent free, through the generous cooperation of Mr. Jerome Belson of the Amalgamated Meat Cutters and Butcher Workmen of North America, AFL-CIO. Mr. Belson and members of his union are the sponsors of the Concourse Village Housing Project. An Extension and Improvement Grant provided jointly by the Vocational Rehabilitation Administration of the Department of Health, Education and Welfare and the New York State Division of Vocational Rehabilitation provided the initial funds for construction and staffing of the project.

The initial phase of the program consists of a screening, followed by a six-week period of evaluation. During this evaluation, the client spends approximately two weeks at the main offices in New York City receiving a battery of written tests, and work samples, plus intensive counseling interviews. He then spends two weeks at the Graphic Arts Training Workshop and two weeks at the Small Business Enterprises Program at Concourse Village.

During the two weeks spent at Concourse Village, the client is given a general orientation. He visits all the stands during his first day. Then, the trainers and rehabilitation counselor work with him during the two weeks at a stand and the stockroom. The following areas are evaluated: 1] working the cash register, 2] addition, 3] subtraction, 4] reading, 5] writing, 6] speaking, 7] holding, 8] packaging, 9] grasping, 10] reaching, 11] bending, 12] stooping, 13] change making, 14] mobility, 15] comprehension, 16] finger and hand dexterity, and 17] peer relations. At the end of this six week period, representatives of the evaluation staff at the main office and of the staffs of the Graphic Arts Training Workshop and the Small Business Enterprises Staff conduct a case conference with the Division of Vocational Rehabilitation's rehabilitation counselor to discuss which area of training, if any, the client should be referred to.

All cases referred to the Small Business project are recommended by a DVR counselor for 20 weeks of Personal Adjustment Training. In both the training stand and the stockroom, he gets familiar with the merchandise, which is a task in itself, since it consists of cookies, hot chocolate, tea, ice cream, cigars, cigarettes, candy, greeting cards, soap, toothpaste, shampoo, mouthwashes, hair spray, paperback books, magazines and newspapers, film, potato chips, cakes, pies, stationery and envelopes.

He also becomes familiar with the prices, ordering procedures, level lists, customer relations and stand and stockroom cleanliness. During PAT, the emphasis of the staff is on observing the client's work habits, appearance and attitude towards other trainees, staff, work, and responsibility.

In addition individual attention is given to those problem areas a client demonstrated during the intensified observations he underwent during the evaluation period. For example, a client is unable to look at a customer when selling merchandise, because of his feelings of inadequacy and poor self-image which results from minimal social contact. During PAT the trainer-counselor would concentrate on building up the client's confidence and give him a chance to observe the trainer looking at and talking with customers. The result of this intensified team effort usually results in the client not only looking at the customer, but also smiling and making informal conversation.

There is continual supervision until we feel the client can be left on his own for short periods of time. Some clients progress faster than others who may be a few weeks before they are left alone for fifteen minutes. The amount of time is gradually increased until he can be left at one stand for hours. Then he would go to another stand for one day and gradually his work schedule would be increased to 5 days at another stand. There is an intercom at all stands, so clients are not on their own by any means. We can tell how they are progressing by the problems they want solved by a trainer, instead of solving it themselves.

During the 20 weeks of employment training the difficulty of tasks is increased up to operating a stand alone. In later weeks the trainees usually learn to close out a register and fill out a daily financial report. By this time, they have observed the process being done many times and training sessions - both OJT and formal training sessions - are given.

Also, at this point, there is increased pressure to reduce the number of errors at the register and in their ordering. The trainee is given more responsibility for doing his own merchandising, display changes, changing of level lists and the handling of what we call a "crisis situation" which is "a dissatisfied customer". Situations arise which are a very normal part of retail business - a paper was not reserved for a customer who had paid in advance, a refund is wanted, a complaint is voiced, old merchandise is sold.

During the final placement phase of six weeks, five objectives are clarified: 1] Placement at a stand away from Concourse Village, under UCP sponsorship, 2] Retention at a vending stand at Concourse Village if the graduate requires more training, or if he appears to be so limited as to be treated as a long term, sheltered employee, 3] Placement at a retail sales facility, such as a boutique, tobacco, candy, flower or grocery store. In other words, competitive employment. 4] Placement in his own business, 5] Placement in staff position as a trainer.

The second program at Concourse Village is the stock and distribution program. Clients in this program are usually more retarded than those in the retail sales and the complexity of their assignments is much less, but accuracy and sometimes speed is very necessary and continually being stressed. During the first few weeks they also would be getting familiar with other people, the program, merchandise and prices. At first, they work directly with a supervisor filling orders for the six stands as well as rotation during the day.

They gradually start working with an advanced trainee and less with a supervisor. They learn to price and put away merchandise delivered by our wholesalers.



Also they learn how to distribute magazines to other stands. At some point, they will be responsible for accepting and signing for incoming merchandise.

Placement objectives for people in this program would be: 1] Placement as a stock clerk in competitive employment, 2] Retention in the stockroom at Concourse Village, 3] Placement with a magazine distribution company.

The third program is porter training. The program was started because we saw a need for cleaning the floors at the stands and training could be provided for apartment cleaning. As more stands are built, there will be an increased need. These people are the most retarded, but they learn to sweep, wash and wax floors, run a vacuum cleaner, dust furniture and venetian blinds, and empty wastebaskets.

### Findings

1. By the end of 1967, 37 clients were referred for evaluation to the Small Business Enterprises Program; 30 were accepted for the program; 7 were found either not suitable for the program or, as a result of a case conference with a Division of Vocational Rehabilitation Counselor, were referred to other programs within the agency.
2. The following table shows the Spring 1968 status and disposition of the 30 clients accepted for training in all subdivisions of the Small Business Enterprises Program.

Table 4.1  
Current Status and Disposition (N-30)

Retail Sales Trainees	12
Stock & Distribution Trainees	5
Porter Trainees	2
Retail Sales Graduate Employees	8
Dropped out of Program	3.

ORGANIZING A SHELTERED WORKSHOP

Presented by

William Goleeke, Executive Director  
UCP of King County, Seattle, Washington

UCPA of King County was started in 1951 by a group of far sighted and concerned parents who felt that their severely-involved youngsters should have some constructive activity to take part in the productive life of the community. A start was made with less than \$5,000.00, with which they hired a full and a part-time staff member to work with 12 young adults whose earning potential was then, and still is, only a small percentage of that of an able-bodied worker. A progressive organization developed through careful and skillful management of dedicated board members. To their everlasting credit, this early board established an unwritten policy of restricting the number of board members to a workable group of 24, plus officers. They made a serious effort to have an equal number of non-parents who could contribute needed skills. At present, we employ 137 handicapped adults and the new structure will permit addition of 50 more. We now have 23 on staff and plan to add 5 more.

The handicapped person is an adult much longer than he is a child. Also, it is generally much more difficult to find a satisfactory program for any severely handicapped adult than it is for children. Therefore, all of us in UCPA are morally obligated to see that constructive and dignified programs are brought into being for CP adults everywhere. These programs should include a sheltered workshop wherever possible, even though many of the workers may be terminal. Other community agencies that are concerned with rehabilitation are still measuring success by the numbers delivered to competitive industry who can be marked "Case Closed." This will never help our wonderfully ambitious cerebral palsied adult. The facts are that the CP who does not measure up to the usual entrance standards are not even considered for employment or extended services.

The main objective of this presentation is to bring to your attention our very successful working arrangement with the Boeing Company, from whom we receive more than 90% of our job contracts. This started in the early 1950's through the cooperation of young Boeing executives who had been recommended as "good prospects for the UCP Board." They felt that some simple work projects could be accomplished with mandatory accuracy by our handicapped people. However, they knew it would be necessary for them to work at their own capable pace and with adequate instruction and supervision. They would also have to be willing to accept a pay scale that would be measured by productive ability. In an article that appeared in the Boeing Magazine of December 1955, the following quotes appeared:

1. "Since it was launched about four years ago, the Boeing effort to make practical use of the skill and industry of handicapped people in current production programs has grown steadily. The United Cerebral

Palsy Workshop, King County's Firland Sanatorium for the Tuberculosis patients, and the Washington State Center for the Blind, are all participating in B-52 and KC-97 production. They make standard type bids for subcontracts and are awarded orders for kinds of work they can handle best.

Data on the contracts already completed show that the work done by the handicapped is consistently excellent. They approach the job with energy and pride, and they deliver a conscientiously high-quality performance."

"The workshops can handle some riveting and drilling, minor assemblies and the simpler of the machine processes. They also do packaging, glueing, envelope-stuffing and the preparation of tags and envelopes by the thousand. As a rule, the Cerebral Palsy Workshop bids most successfully on the highly repetitive type of job which must be done by hand. The wiring of large quantities of identification tags, or the cutting to size of cord rubber, sandpaper and metal sheets, are examples."

2. "At the workshop of the United Cerebral Palsy Association of King County, in downtown Seattle, Boeing normally has 30 to 40 open orders for minor assembly work for KC-97 and the B-52 airplanes. The units include spider assemblies, seals, spool assemblies, fillers, lockwire, door assemblies and snubber cords. More than 22,000 of these parts will be supplied by UCPA. About 30 of the cerebral palsy patients and some, otherwise handicapped, who have been included in the workshop, profit physically and financially from these orders."

The Boeing Company now supplies job contracts to six sheltered workshops in Seattle. They are also contemplating the expansion of this activity to the counties immediately north and south, due to their own expansion in these areas. In 1951, the total contract volume was \$30,000.00, and the estimate for 1967 is \$2,750.00 for 6 shops. Our own volume with Boeing will be close to \$300,000.00 this year. Most of our contracts are part of the production program. There are some of a non-production nature that do not represent a significant portion of our dollar volume. The production parts are subject to the same quality control requirements and schedule performance as other suppliers.

The ground rules established by the Boeing Company say this concerning procurement through their Philanthropic Department:

1. Organizations must be recognized by the Treasury Department as being tax exempt and non-profit.
2. Contracts will be awarded on a competitive basis.
3. The organization must be capable of assuming complete responsibility for providing a quality product and on schedule.
4. Although the company is desirous of doing its part to assist the handicapped within the community, this assistance may not be rendered in a manner that is detrimental to the quality of our product or that would affect our competitive position. Whenever practical, we may extend ourselves to locate and assist such organizations in qualifying for contracts from us.

5. The responsibility for administering our subcontract effort to the various agencies is a philanthropic committee headed by the Material Department. This committee meets monthly.

Other groups are involved in this effort in various degrees. Quality control has a very important part in seeing that the finished items meet Boeing standards and in assisting the UCP Workshop to establish methods for producing a quality product. Others assist with cost-estimating in evaluating the package costs for negotiating purposes; facilities for assistance and consultation in helping a workshop prepare its layout. Many organizations contribute their know-how to a workshop not only in getting started but also in solving production problems. Boeing realizes the importance of a steady flow of work for each shop, and this requires much concentration and effort on their part. They provide weekly contact with the workshops and give technical assistance when needed.

#### Some Suggestions for Starting a Satisfactory Work Arrangement in Any Community

- A. Survey the industrial field so that you will be prepared to offer the right service to the right industry.
- B. Have something to offer regardless of how basic it might be.
- C. Measure your capabilities and stay within the limits of your work force at hand.
- D. Be competitive and make quality and performance speak for you.
- E. If possible, don't rely entirely on one industry, but neither should you jeopardize your existing contract by taking on too much to handle.
- F. Try to have your largest industry represented on your Board, by at least one key member of their management team.
- G. Don't overlook the possible advantage of a direct approach to top management. Many people in key positions are willing and anxious to be of service to the handicapped population.



## CONTINUOUS CARE FOR THE SEVERELY PHYSICALLY HANDICAPPED

Presented by

Harold Conklin, Vice President  
UCP of California

### I. History of Action for Continuous Care

California has long taken forward steps in the care of physically handicapped, due to the willingness of the State Legislature to make provisions for their care. Furthermore, due to the interest of parents and local school boards in various parts of the state, special classes have long been provided to handle the physically handicapped.

In 1943, a group of parents in Northern California felt that the special problems confronting children with cerebral palsy required study. A resolution was introduced into the State Legislature asking for a study to be made by the Department of Public Health and the Department of Education in a cooperative effort. In December, 1944 a combined report was made to the Legislature.

In January 1945, six bills were passed. They provided funds for the establishment and maintenance of two diagnostic and treatment centers for cerebral palsied children together with two state cerebral palsy schools. One of each was to be located in the Northern and Southern parts of the state. Funds were made available for special assistance in helping local schools establish special schools for the cerebral palsied as well as for physical therapists to be provided by the state. Nearly \$1,000,000 was appropriated. As of 1967, the State of California continues to carry on these services.

Even in 1943 many parents recognized that there were still no residential facilities provided by the state for the severely handicapped, mentally normal, children and adults whose parents were no longer able to care for them in their home or because of death were not available to do so. The state has residential institutions for the mentally retarded, regardless of physical disability.

In 1959, the UCP of Los Angeles felt that something should be done. A committee was appointed to study and report on existing facilities. Visits were made to every known facility in Southern California that could offer residential care to the physically handicapped, mentally normal young adult. Very little was available. This committee took the title of "Continuous Care Committee" and came to the conclusion that state action was necessary.

In 1961, the state president of the UCPA asked the chairman of the Los Angeles affiliate committee to head a state committee and provided representative membership from throughout the state. Again, under the heading of "Continuous Care", this committee felt that legislation should be introduced. Previous legislative experience indicated that, rather than try to introduce a bill to provide facilities, which almost surely would have difficulty in getting passed, a longer but surer route was decided upon. The State Society for Crippled Children and Adults were informed of our committee action and lost little time in introducing legislation of which we approved.

On May 25, 1961 a Senate Resolution was introduced: "to determine the extent to which a program of residential care is desirable and necessary to provide treatment, care, education and rehabilitative training for severely handicapped or crippled children and adults of normal mentality. Further, to determine the number of such persons within the state, the nature of institutions and programs required to provide such care and services, whether existing institutions within the state can be expanded or modified to provide such care and services or whether new and separate institutions are required."

A letter-writing campaign by committee members, affiliates and the Crippled Children's Society saw this resolution pass without a dissenting vote.

Considerable time elapsed before the Rules Committee made the assignment to the Senate Fact Finding Committee on Labor and Welfare. They, in turn, charged the State Department of Public Health with doing the work. Our committee met several times with those in charge of making the report for the Health Department and assisted in developing and circulating survey forms. By December 1964 a formal 43-page report was published to be presented to the Fact Finding Committee of the Senate.

Hearings were held by this Senate Committee at which UCPA of California was represented by the Chairman of the Continuous Care Committee along with the Chairman of the Legislative Committee. As a result, a Senate Bill was introduced on April 5, 1965 calling for a four-year pilot study. It stated: "The State Department of Public Health shall initiate and carry out a pilot project in two areas of the state for the purpose of determining the extent of the needs of severely handicapped persons of normal mentality for residential care and to determine how best to meet these needs." The sum of \$100,000 was appropriated for the first and last year with \$150,000 for the second and third. It was stipulated that no funds would be available to erect any structure and that the Legislature would expect a full report of results by January 1969.

On January 3, 1967 a 26-page report was published by the Department of Public Health as a first year report of "The Handicapped Persons Pilot Project". The two areas tested were Sacramento and Long Beach and this report represented findings of case work conducted in the first year by the staff in the two areas. A final report will be started in July, 1968 to be completed and presented in January 1969 with recommendations.

For the life of the Pilot Project an advisory committee to the Residential Care Programs was appointed to review results and advise course of action. UCPA of California was represented on this quarterly meeting by the Chairman of the Continuous Care Committee. These meetings were held in Berkeley at the state headquarters of the Department of Public Health.

During its five-year life, the Continuous Care Committee of UCPA of California has taken as its responsibility to promote legislation for residential care of the physically handicapped and to act as a stimulant to action after legislation was passed. The committee also provided a source of information to the affiliates concerning where care is being provided for the severely physically handicapped and reporting to the annual and semi-annual meetings in the state.

## II. Example of a Residential Facility

A residential facility for severely handicapped has been established by the Spastic Children's Foundation in Los Angeles. On September 5, 1967, they opened

a two-story wing to their present buildings that is housing 49 young men and women on a seven-day basis. 25 young women occupy the upstairs connected with an elevator to the lower level housing 24 young men. All are over 18 years of age with no maximum limit set. Many types of physically handicapped are included not excluding the mentally retarded. The staff for this section involves 35 persons some of whom are on a part-time basis. The building is modern in every respect with large bedrooms housing four residents in each. Facilities include a recreation room, library, music room, laundry, dining room, indoor swimming pool and ample bathroom accommodations. (Financed by 88-164 Hill-Harris.)

Residents have been accepted if they qualify as brain-damaged individuals who do not qualify for any existing public or private agency. Currently, their waiting list is over 200.

A five-sided program exists. This includes academics, therapies, social adjustment, creative living meaning the development of emotional stability and ego image or self appreciation. A program is being developed for the young adults which includes physical education, games with a challenge, adult education with a public school teacher, regular church services and a development of dining techniques. In addition, outside activities are scheduled which include shopping tours. Social responsibilities are emphasized with assignment to routine jobs. Discussion groups with outside leaders are also being scheduled.

The minimum operating costs of the 7-day adult section is estimated at \$250 per month per resident. Three-fourths of the residents are under state subsidy from Aid to the Totally Disabled (ATD). This provides for each \$183 per month to the Foundation. Plans are under way to transfer to the Medi-Cal program which would provide funds of \$14.00 a day per participating resident. Residents not under state aid are paying \$300 per month. The annual anticipated budget for the adult section is \$169,860.

Fund raising has been handled by well-known community leaders who point to programming by professional people which is professionally acceptable. Sources of funds come from many industrial firms, service clubs, mother's auxiliary, and the Spastic Children's Guild, a fund raising group. In addition, many parents have contributed based on their ability to pay.

The success of the Foundation is largely attributed to the fact that a proper balance is maintained on its governing board of one third professionals, one third parents, and one third community leaders.

The Continuous Care Committee feels that the State has a responsibility to care for its handicapped citizens including adequate residential care when parental care becomes too difficult or impossible. Institutions are expensive and may not be the answer. In the meantime, however, private, non-profit agencies may show the way in such projects as exemplified by the Spastic Children's Foundation. Answers should be forthcoming, and to this end the committee finds itself dedicated.



## FACTORS IMPORTANT TO OPERATION OF A SUCCESSFUL SHELTERED WORKSHOP

Presented by

Frank O. Deimel, Executive Director  
UCP of Greater Minneapolis, Inc.

Last year, our workshop invoiced \$362,300 for production and subcontracting services, and \$25,600 for training fees. To do this, we used 6,000 feet of production space and 3,000 feet of warehouse area; an average of 80 handicapped workers daily (including CP); about \$40,000 in equipment, and a staff of about 10 people. After paying production and rehabilitation expenses, we ended up with about \$6,700 left over. We could just as easily have gone in the red by the same amount, because it was due to unbudgeted training fees, rather than to good business practices, that we ended up in the black. So let me say right now that luck is one of the big factors in a successful operation.

A sheltered workshop, like any business, depends a great deal on its management. Our workshop director and his assistant came to us from large manufacturing companies; getting work out is nothing new to them. What is often confusing to the experienced production man new to workshops is that his job is to get the work out with the least capable people who can do it, that you deautomate as much as possible, trying to replace a machine with a man rather than vice-versa, and that the shop is more interested in breaking even than in making money.

The physical plant in which the shop operates is probably less a matter of choice than of circumstance. However, large, unobstructed space is far preferable to small rooms . . . a workshop should project the image of a factory hiring handicapped people, rather than handicapped people trying to look like a factory. Equipment is going to be largely dictated by the type of work to be done. We found that a fork truck of prime importance, also a good loading dock, some hydraulic hand trucks, and several two and four wheel dollies were advantageous. Material has to be handled, and moved, and palletized and shipped or stored. Beyond this, we added air compressors as we acquired machines operated by air and various special purpose machines for our operations. Good friends in various organizations preferred to buy us a power sewing machine than to make a donation, and let us specify what we want.

Too often, a machine no longer serviceable for normal industry is offered as a donation to a sheltered workshop. Beware of this kind of gift! You will end up with a pile of useless junk which will not do what you want it to, and benefits only the donor who takes a tax deduction for it. The people we serve are already handicapped. Give them the best possible equipment to augment their poor manual skills, and the combination can be productive. If no one organization can afford the power conveyor you need, let two organizations go together. The joint gift is sometimes productive of more publicity for the donor organizations than any single gift by either of them would be.

With a staff, a plant, and basic equipment, you are faced with the selection of workers. Be careful here, and realistic! A sheltered workshop is not the solution for every young cerebral palsied adult. In the market place, you should accept the axiom that the customer always comes first. So, you must have people who can get the work done on schedule, with quality, service, and price comparable to outside industry.



On the other hand, what are you trying to do with the shop? In most cases, you would be: Identifying and developing vocational aptitudes, training, providing employment, counseling, and maybe even placement. Basically, you want to make the trainee as self sufficient as possible.

We have two kinds of workers. The regular workshop employees are handicapped, but can produce enough, or have the potential, to earn at least half the rate of an unskilled normal worker. His work is a means toward independence, and we train him to the highest possible level. If he develops to the point where he can be placed, fine. If not, he becomes a long-term sheltered employee. We have many such employees who support themselves, even though their particular handicap might make it impossible to hold a competitive job.

Then we have the "Vocational Activity" group. These are seriously involved people for whom any degree of self support seems rather a far-fetched dream. But they need to get out with other people, to feel they are worth something, to have the therapy of manual activity and the dignity of picking up their lunch pail in the morning like anyone else, and going to work. This group is paid 40¢ an hour, intended as carfare, lunch and pin money, rather than income. If they earn more than this, they are paid more, and more than once a Vocational Activity client has graduated to regular sheltered work. But this group is expensive. They return very little for their pay, and take up valuable production space. As they increased in numbers, we resorted to shifts of one week on and one week off. A new shop would have to think twice about hiring such people.

The cerebral palsied have difficulty on some jobs while performing well on others. Many CP workers can produce nearly as many folded pastry cloths as normal workers can, but fall far behind on soldering or assembly work, where good coordination is much more important than in the gross movements of folding. To augment the weaknesses of CP workers, we have adopted a policy allowing us to hire people with other handicaps. Some mentally retarded, post-polio and mentally ill workers can strengthen the weak areas and allow us to do a full job, while providing work for the cerebral palsied employees. As an example, four years ago, we found that we were spending \$2,500 per month having an outside organization do the sewing for our fabric sampling. We found machines and operators, and today our sewing department takes care of all our needs, while keeping cerebral palsied clippers, counters, and packers busy at jobs that didn't even exist before. We save as much as 15% on production costs, without having to change our price to the customer.

Price is possibly the most important single factor that can make or break a workshop. Consider, for a moment, what an obviously low price does:

1. It allows too little pay for your employees.
2. It subsidizes your customer at the workshop's expense.
3. It gives your customer an unfair advantage over his competitors.
4. It creates friction between labor organizations and sheltered workshops.

An obviously high bid, on the other hand, either loses you the job, or opens the door for negotiation.

The problem of bidding is a complex one. In a normal, competitive business, the components of the bid would be the cost of direct labor, overhead, profit margin and material. In a non-profit organization, the overhead becomes the clouded figure. What is our overhead? We have many expenses a competitive business does not have - i.e. transportation for employees, social worker's wages, subsidized wages for direct and indirect labor, etc. How closely does this compare with the overhead of our normal competitor who pays taxes and has no rehabilitation expense? I cannot answer that, but we have worked out a reasonably satisfactory basis for bidding.

We figure direct labor and overhead at the same rate, add them together and take 1/3 of the sum as a profit margin. Then we mark up material 15% for handling costs, and combine as follows:

Labor	\$ 2.00 per hour
Overhead	<u>2.00 per hour</u>
	4.00
Add Profit 1/3	<u>1.33 per hour</u>
Labor	\$ 5.33 per hour
Quotation	

The shop rate for labor is then \$5.33 per hour. If a normal person produces ten pieces during this hour, we would quote \$.533 per piece, plus the cost of the material.

Such a figure as this is an initial indicator, subject to change after experience. The first time this particular job is done, you may want to time study it with normal staff people, or find out at what rate your customer feels is right. Maybe he will let you know what you are bidding against, what he paid last time, or how much it costs him to do it himself.

Everyone is going to make mistakes, particularly at the beginning, but on subsequent bids more and more experience will be gained, until you can go back into your records and come up with a pretty fair estimate on any kind of a job.

Finally, it is vital to keep good records. At our shop, we have a monthly cost report which lays out every job we do, and shows what it cost, how it compares with our estimated cost, and whether or not we are making enough. We also have a monthly financial statement to consider the workshop operation as a whole. Careful analysis here will show up weaknesses promptly, and allow corrective action to be taken quickly.

THE CONCERN - - - A WORK ACTIVITY CENTER

Presented by

Linda Weber, Director  
UCP Workshop, Cleveland, Ohio

The Concern began in 1958 when the Council of Jewish Women provided funds for three years to establish a pilot workshop for multiply handicapped teenagers and adults who were excluded from other vocational and training resources. Objectives: to provide the opportunity for social and emotional development; to attain maximum limit of productivity and independence within a realistic work environment. In 1961 this program merged with the adult diversional service. In the fall of 1965 the Concern was officially declared an ongoing business enterprise. The goals are still the same, but emphasis has shifted from avocational to vocational. The original six clients now number thirty-three, ranging in age from sixteen to fifty-seven.

The current facility is housed in Vocational Guidance and Rehabilitation Services. Being in this complex affords the use of the pool, A.D.L., therapies, recreational area, conference rooms and maintenance staff. It is located directly off the lobby across from the Sunbeam Shop; thereby being readily on view to anyone entering the building. The shop occupies 4,200 square feet which is free and open except for the glass-walled office. The expanse is heightened by cheerful colors, displays of products and client artwork. The lavatory, kitchen and storage areas are adjacent. The physical plant itself establishes the philosophy of a belief in a quality of living. There is no reason for a functional workshop to be unattractive, colorless and sterile. The nature of the disability served, the psychological aspects involved, warrant a more creative approach.

Direction has been under an M.A. in Art Education with two assistants, having backgrounds in crafts, volunteer and organizational work. The Council of Jewish Women and the Women's Committee of United Cerebral Palsy, "RE:AL Concern," schedule volunteers for a morning or afternoon once a week.

Clients, except for four who use public transportation, are brought by five station wagons. Drivers also make deliveries and aid in maintenance duties not assumed by VGRS. Two clients serve as supervisors and receive a stipend to cover travel expenses.

One day a week is designated as a recreational day, the morning allotted to bowling and swimming. Bowling is regulation league play. Competition is by mail with affiliates throughout the state and a tournament is held in the Spring. The afternoon is given over to art classes, cooking, bridge, discussion groups and games. The avocational aspect must be meaningful and geared to a more adult level. Future plans include theatre evenings, movies and concerts. Due to an increase in business the latter segment has been eliminated except for special programs.

Transportation difficulties dictate the ten months a year, forty-eight hours a month, from nine until two with an hour for lunch. The clients are involved in three valid processes: letterpress printing, silkscreen and subcontract. A segment is devoted to ceramic tile, but in projects such as this, it offers little promise except as a diversional or introductory exercise.

Contract work is sporadic due to the absence of an agent. Silkscreen and letterpress complement each other and the opportunities and possibilities are unlimited. This may be because Cleveland has a market for graphics.

The team approach for combining of abilities is used. One client will put paper in and take it out of the silkscreen or the printing press, a second will draw the paint across the screen or pull the handle of the press and a third will place the item on the rack to dry. The labeling, counting and packaging is also assigned according to ability. The actual organization of designs, screens and typesetting is done by the staff.

The Concern is adding a semi-automatic silkscreen. It will not eliminate a single client, but rather will allow for expansion. It will increase not only client potential but that of the shop by demanding better work habits, creating a professional approach and a sense of productivity.

Articles manufactured range from stationery supplies to recipe cards and an annual forty thousand Christmas cards.

To circumvent the problems of a product-oriented workshop, without a substantial outlet or sales representative, a custom service was developed. Invitations, annual report covers, name tags, ribbons, programs, business cards and posters are designed and executed. Service is provided, not only for the parent agency but for the welfare agencies throughout the city. This affords much needed interaction and exposure. It is ideal public relations, serving as a concrete expression to the community of the capabilities of the handicapped.

Client wages are profit based and determined by the hours registered on the timeclock. They are paid twice a month from sales and Christmas card revenue, which is totaled and dispersed over a six-month period. The current average is twenty cents an hour.

The Concern is above all - Quality! No item is to be sympathy-sold! The standards are those of a specialty studio with definite regard to appealing to the consumer. Packaging and presentation are sophisticated and in good taste. It must compete with, if not excel, the commercial market. The success of a product-oriented program will rely on a professional approach, based on creativity, imagination, common sense, skilled craftsmanship, involvement and a commitment to excellence.

The problems are universal. Lack of funds is the underlying cause. One cannot operate without personnel. Inquiry should be made as to what qualifications are necessary. Hybrids may be needed. The lack of sales outlets can be attributed to the demands made on staff and their subsequent inability to get out and meet the community. It is not logical to handicap the client even further with primitive methods and equipment. If the consideration is placement, this would have to be developed into a self-sustaining business with capacity to pay a minimum wage.



## EVOLUTION OF AN ACTIVITIES PROGRAM FOR YOUNG ADULTS

Presented by

William Parks for UCP of Ohio

### Purposes of the Study

1. To determine the prevalence of cerebral palsy and concomitant disorders in Central Ohio.
2. To assess the needs, abilities, interests and activities of a representative sample of youths in the community.
3. To examine existing programs in order to determine their adequacies in meeting these needs.
4. To suggest means by which inadequacies might be met and to determine priorities for meeting them.

### Findings

1. Revision of earlier prevalence estimates to 1.6 per 1,000 population (or 2-5 per thousand of population under 21).
2. Of 1,260 CP population estimated, present services are reaching 8%.
3. Unmet service needs in: social casework, family counseling, vocational rehabilitation and sheltered workshops, psychological counseling/therapy, recreation and socialization, developmental training and home services for the severely involved.

### Recommendations for implementing services according to need

Research had indicated that past experiences of the severely disabled teen and adult group had been primarily in active, adapted sports, music and dance, outdoor programs stressing nature appreciation and indoor games . . . primarily bingo and shuffleboard. These were game oriented programs with little intellectual stimulation. A first step, then, was to create activities which would stress ideas at the functional level of the individuals. This necessitated presenting adult concepts in terms which clients could understand.

An activities director was employed who took immediate steps, through a diversified program, to raise the interest level of our widely heterogeneous clientele. Guest speakers contributed to the program. One, a local minister, inaugurated a series of lectures on morals and ethics and problems peculiar to the handicapped in finding a purpose in life. Speaking at a level the clients can readily understand, he has been well-received. A library service was installed and the librarian now spends two hours each month reading and discussing books with those who have never learned to read.

Activities such as coin and stamp collecting were developed, not as hobbies, per se, but as learning experiences through lectures and demonstrations, (volunteered by local coin dealer), and researching the history and geography necessary to appreciate the personalities and events pictured on postage stamps.

Home skills such as cooking and dietetics have proven popular to men and women alike. Music is presented in ways such as tracing the development of the ballad form and its reflection in all types of musical expression from the classical through the folk tradition to the present day protest movements. History, thus, becomes a living and rhythmic story rather than a drab lecture.

Science has proven to be one of the most popular program areas...offering, through demonstration and experimentation, insights into the many events which are daily reported on television, but which are incomprehensible unless key background material is known. Not having discussed these topics as children, our clients have never fully understood the concepts.

The formal education classes which had been instructing our adults in primary grade academic skills were curtailed. So was the speech and hearing program which had been ineffectually offering limited therapy to many older clients. In their place, a program was instituted by the speech therapist, which emphasized communication skills in the broadest context, through creative writing, discussion groups, drama, literature, and the publication of a newspaper which often began with a story dictated by one who could not spell . . . transcribed by one who had minimal writing ability . . . sent to a rewrite editor for corrections in grammar and sentence structure . . . and finally sent to another client who could never have initiated a story in the first place, but was able to accomplish, without error, the mechanics of typing the mimeograph masters. Here, as in other areas, the clients work as a team, contributing whatever they can from the initial writing to addressing and mailing . . . with only a minimum of staff supervision.

Formerly impossible assignments have become challenges to ingenuity. A drama group consisting of 28 individuals, 20 of whom have severe speech problems, nevertheless has been able to present the opera Porgy and Bess and the musical comedy Li'l Abner, by the expediency of pantomiming movie sound tracks edited by our staff.

A group of 10 severely involved and, for the most part, wheelchair-bound men have, on their own initiative, formed a club which meets two nights a month for hobbies and an occasional social event. Their first outing, conceived and completely arranged by themselves, entailed a tour of the airport and, assisted by members of the Ohio State Football Squad, were all able to enjoy a flight in small, private, planes as the guest of a local flying instructor. A staff member attends the meetings of this group as an advisor . . . not a supervisor.

Our program is constantly developing. We are not without error. When something fails we discard it, but only after analysis.