#### DOCUMENT RESUME

ED 289 326 EC 201 287

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TITLE Birth to Three Programs in Illinois: The State of the

Art. Executive Summary.

INSTITUTION Western Illinois Univ., Macomb. Coll. of

Education.

SPONS AGENCY Governor's Planning Council on Developmental

Disabilities, Springfield, Ill.

PUB DATE Jul 85

NOTE 49p.; For related documents, see EC 201 288-289.

PUB TYPE Reports - Evaluative/Feasibility (142)

EDRS PRICE MF01/PC02 Plus Postage.

DESCRIPTORS \*Disabilities; Early Childhood Education; Eligibility; \*Intervention; Models; \*Program

Development; Program Evaluation; Recordkeeping; Staff

Development; State Legislation; \*State Standards

IDENTIFIERS \*Early Intervention; \*Illinois

#### **ABSTRACT**

This document contains an executive summary of a study designed to: determine the status of early intervention (birth-to-3) programs for handicapped children in Illinois, to make recommendations for future planning, and develop training modules focused on the findings. It discusses the study's rationale, method, and design; estimates incidence rates of handicapping conditions; and reviews state regulations. The document summarizes study results in the following areas: rural and urban program differences, number of children served, service delivery strategies, screening and referral, child evaluation, transition, parent involvement, staff preparation and certification, staff development, staff morale, and funding. Recommended standards for comprehensive birth-to-3 early intervention programs are provided, along with an outline of a model program's components in the areas of program structure, handicap identification, eligibility determination, program development, program implementation, transition, evaluation, and administration. The document concludes with recommendations to improve birth-to-3 programs in Illinois in the areas of approach, standards, personnel certification, record-keeping, funding and budgeting, eligibility criteria, staff development, program evaluation, and program characteristics. (JDD)



# Sweenthe Summary

# Birth to Three Programs in Ulinois: The State of the Art

Patricia Hutinger
Sue Mietus
Richard Rundall
Bonnie Smith-Dickson

Results of a study funded by the Governor's Planning Council on Developmental Disabilities

Patricia Hutinger, Principal Investigator

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# **EXECUTIVE SUMMARY**

Birth to Three Programs in Illinois
The State of the Art

bу

Patricia Hutinger
Sue Mietus
Richard Rundall
Bonnie Smith-Dickson



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# Executive Summary

# Introduction

Public responsibility for providing services and opportunities to handicapped individuals is an issue which has provoked widespread interest over the last several years. That government agencies and institutions are acknowledging and acting on that responsibility can be confirmed by examining legislation enacted over the last 20 years.

Beginning during the Kennedy administration with the passage of PL 88-164, the Facilities for the Mentally Retarded Act, and continuing through the establishment of the Bureau of Education for the Handicapped (now the Office of Special Education Programs) and the passage of the Handicapped Children's Early Education Act (PL 90-538), growing interest in equal rights for handicapped persons was apparent. In the early 1970s, more legislation was passed and definitions of handicapping conditions were broadened. Public Law 94-142, a piece of landmark legislation, was signed in 1975. In addition to offering unprecedented incentives to state and local school districts to provide special education services for young handicapped preschool children, PL 94-142 specified conditions and circumstances which must be met in order to improve the education provided for these children.

Public Law 94-142 mandated special education services for school-aged children; however, the definition of "school-aged" varies from state to state. By 1982, only 22 states had mandated provision of educational services for children under the age of 5, and of those, only 8 began providing services at birth. Of those eight, Maryland, Michigan, Iowa, and Nebraska are the only states currently providing comprehensive services from birth (Anderson & Black, 1981). The other four states provide services from birth only to specific populations, such as hearing impaired or blind infants. Public Law 98-199, passed in 1984 and amending PL 94-142, may provide further impetus to states to lower the mandate to birth by providing incentive grants to the states through the state educational agencies or other responsible state agencies to assist in planning, developing, or implementing an Early Childhood State Plan for a comprehensive delivery system of special education and related services to handicapped children from birth to 5 years of age. Figure 1 on the next page details the requirements of this law.

That legislation is now pending in Illinois concerning special education from birth is not surprising. Illinois has long been in the forefront in providing special services for handicapped preschool children. After the Handicapped Children's Early Education Program (HCEEP) was established in 1968 to encourage the development of innovative model projects designed to serve young handicapped children, one of the first such projects, the Peoria 0-3 Project, was established in Illinois. It was soon followed by Project RHISE in Rockford in 1973 and the Macomb 0-3 Rural Project in 1975. All three of these projects made the transition to outreach (training) programs after the three-year period of their demonstration grants was completed; the Macomb Project is the only rural model birth to 3 program in the country which has



# Figure 1: Comprehensive Service Delivery System Defined

Public Law 98-199 allocated monies through which grants were made to each state through the state educational agency or another responsible state agency, to assist the state in planning, developing, or implementing an Early Childhood State Plan for a comprehensive delivery system of special education and related services to handicapped children from birth to 5 years of age. The requirements which states must meet in their comprehensive service delivery system plans include the following:

- A statewide system for identifying and locating, as early as possible, children who are handicapped or at-risk of being handicapped. This includes the prenatal period if there is evidence that a child will be born handicapped;
- 2. Comprehensive and continuing assessment and diagnosis of children who are identified as handicapped or at-risk of being handicapped;
- 3. Special education and related services appropriate to each handicapped child's developmental level and handicapping condition;
- 4. A continuum of alternative placements to meet the individual needs of handicapped children for special education and related services;
- Involvement of parents in the planning, development, and implementation of the education and services provided to their handicapped children;
- A personnel development program to ensure appropriately trained instructional and supportive staff;
- 7. Coordination of the activities of educational, health, social services, and other agencies to ensure effective use of available services and to relate service delivery programs to state and local planning;
- 8. Information concerning the needs of handicapped children and the availability of services; and
- Ongoing evaluation of the effectiveness of the services and programs provided to handicapped children and others involved in their education and care.



been accredited by the Joint Dissemination Review Panel (JDRP) of the United States Department of Education.

# Overview of the Study

The Governor's Planning Council on Developmental Disabilities recently announced in <u>Developmental Disabilities Directions</u> (January 1985) that "policy directions and alternatives for the future should be the primary role of the Council" (p. 1). Evidence of this having been a central issue prior to the announcement can be seen in the funding by the Governor's Planning Council on Developmental Disabilities of the present study, begun in October, 1983. The study represented an initial step in marshalling resources for systematic early intervention programming. The goals of the study were to gather information needed to determine the status of Illinois birth to 3 programs, to make recommendations for future planning, and to develop two training modules focused on the findings. These goals were accomplished through the completion of the following activities:

- 1. A two-level survey (questionnaires and interviews) of Illinois birth to 3 programs through administrators, direct service staff and parents of children enrolled;
- 2. A review of related early intervention literature;
- 3. A review of practices and standards of agencies involved in early intervention programs in Illinois;
- 4. A review of early intervention standards and policies in other states;
- 5. The examination of nationally recognized exemplary birth to 3 model programs;
- 6. The development of two training modules for use by Illinois service providers;
- 7. The operation of an advisory council or panel of Illinois experts in birth to 3 services.

The two-level survey design was based on a similar but earlier study of Illinois preschools (Hutinger & Swartz, 1980a & b), funded by the Illinois State Board of Education to study the state of the art of programs for handicapped 3- to 5-year-old children in the areas of service delivery, parent involvement, and transition. The present birth to 3 study, descriptive and exploratory in nature, was intended to establish a baseline for future work. Manipulation of experimental conditions was not intended.

# Rationale

Basic to the provision of services to and the treatment of the handicapped infant and toddler is the tenet that early identification of the



child and intervention with the child and her family can ameliorate or minimize the long-term effects of her handicapping condition. The effectiveness of early intervention has been demonstrated by many studies.

Among the earliest studies of intervention are those of Skeels and Dye (1939) and Kirk (1958) and the follow-up studies of Skeels (1966) and Kirk (1977). Skeels' and Dye's study involved the identification of two groups of retarded children under the age of 3 who were in an orphanage receiving very little stimulation from a consistent caretaker. The experimental group was removed and placed in a situation where they received stimulation while the other was left in the orphanage. A year and a half later, the experimental group had gained an average of 26 IQ points. When Skeels followed up the groups 21 years later, he found that all but one of the experimental group had graduated from high school and were self-supporting. The average school attainment for the control group was third grade, and five of the control group were still in institutions for the retarded.

In a now classic study, Kirk, in 1958, studied an experimental group of retarded children attending a preschool intervention program and a preschoolaged control group who had no program. Nearly 20 years later, Kirk followed up the children and found that 70% of the experimental group had gained 10 to 30 IQ points, while the IQ scores of the control group showed a decline of similar proportions. Even taking into account the fact that Kirk's study was done with 3- to 5-year-olds, these longitudinal studies would indicate that not only is early intervention immediately effective, but also that the effects tend to last.

Bricker and Sheehan (1981) followed severely impaired children from 6 months to 5 years of age who participated in a daily intervention program for at least two years. They found significant gains in the children's development. Rosen-Morris and Sitkein (1981) followed a group of profoundly handicapped children involved in an intervention program over a 4 year period and also found that the children demonstrated significant developmental gains. Dunst, Vance, and Gallaher (1983) collected data on 625 children who had been served in infant programs over the past 10 years and found that 90% of those children had the potential to make significant developmental progress, even though they had all been at high risk for institutionalization.

McNulty, Smith, and Soper (1983), in a study completed for the Colorado Department of Education of birth to 5-year-old children over a 3 year period, found that 31.4% of the children served in the 11 sites were able to go into a regular classroom at age 5; 37.1% were able to be served in regular classes with support; and only 31.4% went into special education classes. The estimated savings per pupil averaged \$1,184.

The cost benefits of early intervention to the taxpayer are compelling. The Littlejohn study (1982), commissioned by the U.S. Department of Education, indicated that 67% of the students studied who had received early intervention services required less intensive services later. Estimates of cost savings over a child's school lifetime range from \$14,819 (Weber, 1978, cited by Bricker, Bailey, & Bruder, in press) to \$16,000 (Wood, 1981, cited in McNulty, et al., 1983; Garland, Stone, Swanson, and Woodruff, 1981).

The cost of long-term remedial treatment and special care for handicapped school-aged children and adults is far greater than the cost of early



intervention which frequently makes productive citizens of the children who would otherwise go through life dependent upon others (Washington Superintendent of Public Instruction, undated).

While the data from these studies tends to be convincing evidence of the efficacy of birth to 3 early intervention to its proponents, there are those with reservations. Bricker, et al. (in press), Dunst and Rheingrover (1981), and White, Mastropieri, and Castro (1984) all point out that a majority of the studies have methodological weaknesses in design, measures, populations, analysis, and the relationship between variables. Additionally, the fact that the most valid research is on the at-risk population leaves the question of the effectiveness of very early intervention on children with identifiable handicaps open to criticism. Criticism does not mean that the research is invalid or that the results are erroneous. The critics, in fact, clarify the problems inherent in evaluating the effectiveness of services to the birth to 3 population with special needs. For example, severely handicapped children may show little or no progress on currently reliable and valid assessment instruments used for research purposes. This does not mean that severely handicapped children do not benefit from being served in an early intervention program, or that the early intervention program is ineffective because it cannot show developmental progress with the assessment instrument. It does mean that the requirements of quantitative research methodology may be an inappropriate means for demonstrating the effectiveness of early intervention programs, or it may mean that instrumentation is inappropriate.

The argument that qualitative design may be more appropriate is gaining increased acceptance (Patton, 1980; Guba & Lincoln, 1981). Control groups, standardized tests, random sampling, and statistical analyses based on normal distribution assumptions are in themselves inaccurate measures of a population made up of unique children and families in unique situations. Among others, Fewell (1983) discusses measurement problems with handicapped infants in detail. The argument between quantitative and qualitative researchers which has gained momentum in the past 5 years can be expected to continue, with no clear victors in the immediate future. It is doubtful that some problems in documenting the effectiveness of early intervention will ever be entirely eliminated. If we recognize this, it may be easier to accept research findings as indicators or approximations of the truth, within the limitations which are inherent in the very early intervention process.

# Method and Design

Information was collected for the study from a review of appropriate literature, a review of state agency guidelines in Illinois, a review of birth to 3 legislation and standards in other states, the identification of existing birth to 3 early intervention programs in Illinois, and data collected from a two-level survey sent to administrators, direct service providers, and parents of children enrolled in existing Illinois programs.

Locating and identifying birth to 3 programs was a major and time-consuming process. Programs are funded by a variety of means; some programs are components of larger agencies which provide many services to people of different ages; and a number of state and other agencies are involved in



funding or regulating birth to 3 programs. Thus, there was no single source from which a list of all birth to 3 programs could be obtained. Initially, through a survey of pertinent state agencies and other sources, 80 programs which were likely to be birth to 3 early intervention programs were located, and Level I questionnaires were sent to them. As the study progressed and interest in it grew, an additional 23 programs were located and surveyed. Of these 103 programs, returns from 14 indicated that they were not comprehensive early intervention programs, nor did they identify themselves as such. Finally, a total of 51 sites returned at least one questionnaire. Using U. S. Census standards, 33 of those sites were classified as urban and 18 as rural.

The packets of Level I questionnaires sent to each program consisted of one questionnaire to be completed by an administrator, four questionnaires to be completed by direct service providers, and four to be completed by parents of children enrolled in the program. Nine of the 51 sites returned all nine of the questionnaires; 23 returned at least one questionnaire in each category. It is important to note that some sites do not have enough staff to fill out five forms. Particularly in rural programs, the person designated as program administrator often also functions as the service provider. Consequently, return of all nine completed questionnaires was not expected from all sites. Responses were received from 37 administrators, 133 service providers, and 118 parents. For purposes of comparison, the programs were categorized according to U. S. Census standards as urban, rural, and urban-rural (serving children from both demographic regions); the two school-based programs were placed in a separate category. A similar Level I questionnaire was sent to 19 High Risk Units at hospitals serving residents of Illinois. Twelve of them responded, but one of the twelve was a follow-along program rather than a high risk unit. Figure 2 contains a summary of Level I and II respondents.

Content of the four questionnaires (administrators, service providers, parents, and high risk units) was different but similar, and related to characteristics of staff, agency demographics, child and family demographics, screening and referral services, program components for children, family services and involvement, administrative concerns, staff development, and budgetary matters.

Originally, 16 sites were randomly selected from the 51 responding sites for Level II interviews, blocked on rural and urban locations. However, as a result of cancellations because of discontinued funding, sick children, and scheduling conflicts, interviews were ultimately conducted with 15 administrators, 14 service providers, and 14 parents. Subjects came from 8 urban and 7 rural sites. The Level II interview forms consisted of open-ended questions designed to elicit more in-depth information about topics of interest in the study.

Letters requesting information regarding the role of the agency in the provision of early intervention services were sent to seven state agencies initially identified as possible sources of standards for early intervention programs. Those agencies were the Department of Children and Family Services (DCFS), the Department of Mental Health and Developmental Disabilities (DMHDD), the Department of Public Aid (DPA), the Department of Public Health (DPH), the Department of Rehabilitation Services (DORS), the Division of Services to Crippled Children (DSCC), and the Illinois State Board of Education (ISBE).



# Figure 2: Illinois Birth to Three Program Respondents - 1984

| l eve | l I Survey                | Respor  | 1SPS  |     |      |       |      |      |     |    |     |     |
|-------|---------------------------|---------|-------|-----|------|-------|------|------|-----|----|-----|-----|
| Leve  | i i baivey                | nc spoi | 1505  |     |      |       |      |      |     |    |     |     |
|       | Parents .                 |         |       |     |      |       |      | •    | •   |    | •   | 118 |
|       | Staff                     |         |       |     |      |       |      | •    | •   |    | •   | 134 |
|       | Administra                | ators.  |       |     |      |       |      | •    |     |    | •   | 37  |
|       | High Risk                 | Units   |       |     |      |       |      | •    | •   |    | •   | 11  |
|       |                           |         |       |     |      |       |      |      |     |    |     |     |
| 51 Pı | rograms Re                | sponde  | d (57 | %)  |      |       |      |      |     |    |     |     |
|       |                           |         |       |     |      |       |      |      |     |    |     |     |
|       | Urban                     | 33      | 3 -   | 659 | of   | pro   | gram | is r | esi | on | dir | ng  |
|       | Rural                     | 18      | 3 -   | 359 | of   | pre   | gram | is r | est | on | dir | ng  |
|       |                           |         |       |     |      |       |      |      |     |    |     |     |
| Leve  | l II Interv<br>(Random sa |         | of Le | vel | I re | espoi | nden | ıts) | )   |    |     |     |
|       | Parents .                 |         |       |     |      |       |      |      |     |    | •   | 14  |
|       | Staff                     |         |       |     |      |       |      | •    |     |    | •   | 14  |
|       | Administr                 | tone    |       |     |      |       |      |      |     |    |     | 15  |



Throughout the study, an Advisory Panel of Illinois birth to 3 authorities gave assistance and advice.

# Who Should Be Served

Estimates of incidence rates of developmentally disabled, delayed, and at-risk children vary dramatically. This is largely because there is little consistency in definition of these terms. Various institutions, agencies, and individuals include or exclude different categories and conditions. Bergsma (1973), for example, indicates that there are over 4,000 causes of severe handicapping conditions which would cause a child to require special education. As various categories are included or deleted, estimates change. In 1983, there were 178,820 live births to residents of Illinois (Illinois Department of Public Health Vital Records). Of these 12,878 (7.2%) were low birth weight, a figure some use to estimate the numbers of infants who will require early intervention.

When children who are at-risk for developmental delay or disability are added to the numbers of identifiably handicapped, the 12% of children who will need special education (as supposed by PL 94-142) seems likely to be an underestimation. Children who are developmentally at-risk include those born too early and too small; children born by caesarean section; children born too late; children born of teenaged parents or mothers over the age of 35; those born of mentally ill, disabled, or alcoholic parents; those whose parents are living at or below the poverty level; and children who are the victims of abuse or neglect

# Review of State Agencie

Currently there are no state agency regulations which apply directly to all early intervention programs in Illinois serving birth to 3-year-old children with special needs and their families. Figure 3 on the next pages shows the population served and regulations stipulated by the seven Illinois agencies which provide or fund the provision of birth to 3 services. Those regulations which do apply to some of the early intervention programs are of a general nature and often apply to a child of any age or to adults as well as children. For the most part, such regulations as do exist do not address the entirety and the quality of the components of early intervention services. Inadequate regulations result in a disparity in the availability, quality, and provision of early intervention services from one program to another. Some programs are probably less effective than they could be; therefore, some children are affected, if not negatively, at least not as positively as they could be. The goal of every early intervention program should be to maximize the development of each child served and to minimize, insofar as possible, the effects of any handicapping condition. The lack of comprehensive, inclusive regulations for early intervention services means that some programs are failing to meet their goal with some or all of the children they serve.



Figure 3: Summary of Illinois Agencies' Services and Standards to Handicapped Children from Birth to Three

| AGENCY  | SERVICES PROVIDED  | то wном  | STANDARDS OR REGULATIONS   |  |  |  |  |
|---|--|--|--|--|--|--|--|
| Department of Children and Family Services (DCFS) | as needed  | <ol> <li>wards of the state for<br/>whom DCFS is guardian</li> <li>children for whom DCFS<br/>must provide supplemental<br/>adoption fees</li> </ol> | responsible for licensing day care centers (affects early intervention programs only if children remain in the center without parents present) |  |  |  |  |
| Department of Mental<br>Health and Develop-       | 1) grants-in-aid   | 1) community support services  | 1) same for children's services as for adults  |  |  |  |  |
| mental Disabilities<br>(DMHDD)                    | <pre>2) federal and state    special education    funds</pre>  | 2) educational programs at state mental health and developmental disabled facilities and zone centers  | <ol> <li>educational programs are subject to special education regulations</li> </ol>  |  |  |  |  |
| φ   | 3) individual care grants  | 3) individual children who have been placed in pri-<br>vate residential facilities   | <ol> <li>encourages Commission for<br/>the Accrediation of Reha-<br/>bilitation Facilities</li> </ol>  |  |  |  |  |
|   | <ol> <li>activities of Illinois<br/>Institute of Develop-<br/>mental Disabilities</li> </ol>                             |  | (CARF) accreditation rather than developing own  |  |  |  |  |
| Department of Public<br>Aid (DPA)                 | <ol> <li>funding and travel re-<br/>imbursement for medi-<br/>cally prescribed</li> </ol>                                | <ol> <li>infants eligible for<br/>DPA financial assistance</li> </ol>  | only apply to specific therapy providers (must be medicare/medicaid registered)  |  |  |  |  |
|   | therapies 2) early periodic screen- ing, diagnosis and treatment screening (EPSDT)                                       | <ol> <li>infants whose mothers are<br/>receiving Aid to Dependent<br/>Children</li> </ol>  |  |  |  |  |  |
| Department of Public<br>Health (DPH)              | <ol> <li>screening services</li> <li>medical care</li> <li>PKU treatment products</li> <li>follow-up services</li> </ol> | <ol> <li>children with phenylketonuria,<br/>hypothyroidism, galactosemia</li> <li>infants in perinatal high<br/>risk units</li> </ol>                | screening is done by local DPH personnel; hence no regulations with general application  |  |  |  |  |



Figure 3: Summary of Illinois Agencies' Services and Standards to Handicapped Children from Birth to Three (continued)

| AGENCY   | SERVICES PROVIDED  | ТО WНОМ   | STANDARDS OR REGULATIONS   |  |  |
|--|--|---|--|--|--|
| Department of Rehabil-<br>itation Services<br>(DORS)   | <ol> <li>Illinois School for<br/>tge Visually Impaired</li> <li>Illinois School for<br/>the Deaf</li> <li>Illinois Children's<br/>Rehabilitation Center</li> </ol> | <ol> <li>children in need (few infants; residential program)</li> <li>same</li> <li>not early intervention, but may refer infants for early intervention after diagnostic work-ups</li> </ol>   | none for early intervention  |  |  |
| Division of Services<br>to Crippled Children<br>(DSCC) | <ol> <li>funds</li> <li>diagnostic and<br/>therapeutic services<br/>through early inter-<br/>vention programs</li> </ol>   | income-eligible infants with a variety of handi-capping conditions  | none which apply to programs; certification or licensing as appropriate required of individual therapy-providers |  |  |
| Illinois State Board of Education (ISBE)               | permissive services through local school dis- tricts or special educa- tion cooperatives (few districts elect to pro- vide infant services)                        | only those who display these exceptional character- istics: visual impairment, hearing impairment, physical or health impairment, specific learning disabilities, educa- tional handicap, behavior disorder, mental impairment, multiple impairment | same as for spicial education of any aged child  |  |  |

# Discussion and Summary of Results

Differences between rural and urban programs. We expected to find differences between rural and urban programs in Illinois and we found that they do exist. Urban programs generally have more personnel to work with families. Rural programs have fewer resources, especially specialized personnel, perhaps because the specialists frequently choose to live in urban areas rather than in the farmlands. Rural programs often solve the problem of the scarcity of specialists by contracting with them on a part-time basis. Surprisingly enough, there were no real differences in the number of years rural and urban programs have been serving the birth to 3 population. Nor were there differences among parents in what they thought about the program -- rural and urban parents alike indicated that the birth to 3 programs had helped their children.

As Illinois residents are aware, the acute differences between urban Cook County and "downstate" Illinois extend to most aspects of life, and birth to 3 programs are no exception. Urban programs are more likely to serve a number of children with the same or similar disabilities, whereas rural programs will more likely serve children with a wide range of disabilities rather than a large population with a similar disability. The study found, also, that significantly larger numbers of children in urban programs are from both single-parent families and teenaged-parent families than children in rural programs.

There are differences in the service delivery staff between urban and rural programs as well. For example, staff members in rural programs have been employed in birth to 3 early intervention programs significantly more years  $(\bar{x}=4.38)$  than staff members in urban programs  $(\bar{x}=2.24)$ . This is of great interest when one considers that there are no differences in the number of years the programs have been in operation. There may be greater turnover of staff in urban programs than in rural programs, or urban programs may have expanded more rapidly than rural ones in the past two years.

While parents and service delivery staff report that urban early intervention programs offer more services or activities than rural programs, the administrators indicate the rural agencies offer significantly more services and programs in addition to early intervention services than do urban programs. It is possible that parents and staff were focusing only on the activities offered to birth to 3 clients, while the administrators were looking at the total structure of their agencies. Additionally, it may be that urban programs tend to provide only services for the birth to 3 population, while rural agencies provide a wide range of services for the entire handicapped population across a wide age span in a particular geographical area. In any case, administrators have a different perspective on the programs from parents and staff.

Waiting lists exist in both urban and rural areas, but there are significantly more children on the lists in urban areas than in rural areas. Administrators indicated that there was not much difference between the two in the average length of stay on waiting lists. However, it is clear that rural children who are referred to a birth to 3 program for services actually begin receiving services far sooner than urban children. This finding, mentioned by interviewed parents, was repeated by both service staff and administrators. There is some question of whether this is consistent with the remainder of the



data related to the time between referral and when services begin. parents report that their children wait a significantly longer time to receive help than rural children. Service delivery personnel and administrators mirrored the parents' report of long waits for services in urban areas. parents reported that their children wait significantly longer time, after referral, to be screened than do children in rural areas. On the average, it takes an urban family 6.85 months to receive educational services after referral. In rural areas, the average wait is only 2.77 months. Whether the wait is partially due to the population density in urban areas and the concomitant occurrence of a greater number of eligible children and an inadequate number of programs available, or whether identification processes are operating effectively but services after identification are not readily available is not known. However, at that point in a family's experience when anxieties about their disabled infant are high and the future is unknown, when there are questions about needed everyday activities and how to perform them, the length of time between referral and services needs to be reduced. The data lead one to believe that, at least in this instance, those who live in rural areas are more likely to be receiving birth to 3 services at a time when they are needed than are their urban counterparts.

Urban parents report spending more time in birth to 3 program activities than do rural parents. They also report that more program activities are available for them. A significantly greater pe centage of children and families in urban areas use agency-provided transportation than do those in rural areas. However, there were no significant differences between rural and urban families and the distance they travel to receive services. One would expect that rural families would travel greater distances, but this did not seem to be the case. Whether or not rural staif travel greater distances than urban staff was not investigated and is a question which should be considered.

There are some differences in the evaluation of the physical facilities of programs in rural and urban areas. For example, when rating the amount of space available in the birth to 3 program, urban parents rated the amount of space significantly lower than parents in rural programs, but there were no real differences in their ratings of parking, atmosphere, convenience of the location or physical accessibility. Urban staff reflected the parents' perceptions of program space. But rural staff members rated the quality of their program atmosphere higher than urban staff. Rural staff members also rated their program location as significantly more convenient than did urban staff.

The age at which both rural and urban children begin receiving services, according to parents, is about the same. Rural children are on the average 9.88 months old; urban children are 9.04 months. The number of children served in rural and urban programs was about the same at the time the Level I survey was completed. Urban staff reported an average of 44.81 children on their program's caseload while rural staff reported an average of 41.84. However staff members in urban areas reported serving a significantly greater number of children per week (19.10) than staff in rural areas (11.19).

Number of children served. The administrators were asked to indicate how many birth to 3 children their programs were serving at the time of the survey. Urban programs reported serving an average of 46 children, and rural programs reported an average of 32.6, indicating no significant difference.



The total number of children served by the 37 programs in 1983 was 3305, an average of 84.7, and the total number of children served in 1982 was 3024, an average of 81.7. Urban administrators reported serving a total of 727 children in 1983 ( $\overline{x}$  = 80.8) and rural administrators reported serving 1193 ( $\overline{x}$  = 74.6). In 1982, urban administrators served 781 children ( $\overline{x}$  = 86.7) and rural administrators served 938 ( $\overline{x}$  = 58.6).

The average number of children that the administrators reported serving at the time of the survey, 48, is lower than the averages reported for 1983 and 1982 because it does not take into account children who left the programs before or came into the programs after the survey was completed. It can be taken as reflecting the number of children that are on a caseload in an intervention program at a specific point in time, and is comparable to figures cited as current case load by direct service staff.

Service delivery strategies. Illinois programs reflect a range of services. Administrators mentioned home-based programs (15 rural and 6 urban), center-based programs (8 rural, 8 urban), consultive services (3 rural, 2 urban), satellite services (5 urban) most often. As the numbers indicate, some programs offer both home-based and center-based services.

When asked about the models used by their birth to 3 programs, administrators mentioned the three Illinois HCEEP models and the CARF standards. There was some misperception of the meaning of the term "model." A developmental scale is not a model of program services. Service delivery personnel also mentioned a wide range of models, listing the three Illinois HCEEP models mentioned earlier. They also mentioned a number of isolated parts that do not constitute comprehensive services. It would seem that programs need specific training on the components of comprehensive services with intensive work related to curriculum and its accompanying philosophy.

Screening and referral. According to the majority of parents who returned Level I surveys, it was their own idea to refer their children for services. Only five of the parents indicated that they were referred as a result of mass screening. Of the 118 parents responding to the Level I survey, 49 (36.8%) reported that they had been referred to the program by a physician; however, of the 14 parents interviewed during the Level II survey, 12 (85.7%) reported having been referred or told to refer themselves by physicians.

Few staff and administrators indicated that they used mass screening to identify children in need of services. More than half of the service delivery staff indicated that their program had no formal child find plan. The bulk of the service staff indicated they screen on a referral basis. A smaller group of service staff indicated that their program accepted the screening done by a referral or resource agency.

A wide range of screening instruments was reported as being used by Illinois birth to 3 programs. In many cases, the screening instruments are inappropriate. For example, some programs use the Bayley Scales of Infant Development as a screening device. The use in inappropriate ways of measures that enjoy some degree of credibility seems to be the general practice rather than the exception in a large number of Illinois programs. The use of



instruments designed as screening tools to evaluate child change is also reported frequently. Misuse of tests is widespread. The criticism of tests has become almost a national pastime for birth to 3 service delivery personnel, and yet this is an area where inservice on the use of appropriate tools is critically needed. It is unlikely that a new test needs to be developed, but it is necessary that programs agree on standard recognized screening instruments and procedures. Service delivery staff and administrators alike must have the purpose of screening clearly in mind when planning for that activity.

Administrators' responses demonstrated a clearer understanding of the eligibility requirements of birth to 3 programs than did service providers' responses. All but one service provider indicated that the program had criteria for acceptance of a child into the program. But a few programs have criteria that specifically discriminate against a particular population. For instance, one response indicated that children were accepted into the program if the child "exhibits NO severe handicap," while another indicated that the child and family "must be English speaking."

<u>Child evaluation</u>. While urban programs involve a greater number of staff members in the evaluation and staffing of the children in their programs as compared with rural programs, most of the parents, across all programs, indicated that they were active participants in the staffing process to help develop goals for their children.

The issue of assessment, to determine where the child is functioning developmentally, is another question. Whether doing initial assessments on children beginning the program, or doing systematic testing for measuring child change, Illinois programs in general responded similarly in the section on screening. Over 25 different instruments were cited as being used by service staff. Administrators also report a wide variety of tests in use. Again, the problem lies in the fact that many of the instruments cited are not appropriate for such assessment. The Denver Developmental Screening Test, an instrument which can be appropriately used for screening purposes, is used by many as an instrument for accomplishing child assessment. This is an inappropriate use of the Denver Test. The results of this study in regard to the use and misuse of screening, diagnosis, and evaluation closely parallel the rindings of the earlier study on Illinois preschool programs for handicapped children (Hutinger & Swartz, 1980b). Again, training and agreement on tests for use in birth to 3 programs need to be addressed by agencies responsible for funding and monitoring those programs. Adoption of appropriate tools for use in programs is essential.

<u>Transition</u>. While administrators report that they have a standard transition process scheduled, parents and staff report problems with the transition process. Lost records, late notification of scheduled staffings, and other problems were reported far more often than would be the case if the transition process worked effectively for programs.

Parent involvement. By and large Illinois birth to 3 programs, at least as they were reported in the Level I surveys, provide a wide range of parent involvement activities. Staff indicate that at least 22 different types of



parent involvement and services are offered to families. They also report that families in rural areas become significantly more involved than families in urban areas. According to parents, urban programs offer more activities than rural programs. Eighty-three percent of the parents indicated that "training in working with my child" and "provision of information" were the most frequently offered activities. Sixty-three percent of the service delivery staff indicated that there was a parents' orientation process available for newly enrolled parents.

Most parents indicated they were given activities to do with their child by the program staff, and over 55% of the 118 parents (65) indicated that they were their child's primary teacher. On the other hand, fewer than half of the staff (54, or 42%) said that the parent alone was the child's primary teacher. Thirty-nine of the staff members (30%) indicated that they were the child's primary teacher. At the present time, many professionals and parents alike are taking the position that the parent is the child's primary change agent and should work with the child, at least some of the time. This is not to say that the parents' need for respite is not acknowledged, nor that the parents' need for professionals who know what they are doing in the therapeutic and educational sense is diminished. It does mean that parents' concerns and wishes are primary in working with the infant and toddler with disabilities.

Generally, parents reported that they were involved with their child's program and that they would like to have greater involvement. Both administrators and staff indicate that parents should be highly involved in the program and goal setting process, but acknowledge that in reality parents are involved to a lesser extent than would be ideal.

While slightly more than half the direct service staff indicated that their program had a formal procedure for obtaining parent feedback about the program on a regular basis, the definition of "formal" was quite general. Family assessment is said to be used on an informal basis in many programs, yet little or no information that could be quantified or compared across programs or within programs was collected. The need for useful, valid, and reliable family assessment measures is apparent in Illinois birth to 3 programs.

Parents do rate their participation in the birth to 3 programs in a positive manner. The vast majority (95%) ranked their satisfaction with the early intervention programs above average. Eighty-one percent of the parents said the programs had helped their child very much. When parents were asked about procedures used to evaluate their child's progress, 99% indicated that the program staff does the evaluation and almost as many parents indicate that they participate in that evaluation in some way.

Staff preparation and certification. Job descriptions among direct service staff vary widely, as does their experience in early intervention programs for both birth to 3 and older children. Over 21 different titles or roles were cited. They also reported a wide range of training, ranging from five who had completed high school to one who held a doctorate. Staff hold a wide range of certifications which range from certified elementary education or early childhood teachers and teachers with specific certificates in Special Education to registered physical therapists.



Administrators also reported several different job roles. They varied widely in experience, with a range from less than one year to over 20 years reported as the length of time they have been administrators in early intervention programs. They hold a variety of degrees ranging from an associate degree to a doctorate. They also hold a wide range of certifications ranging from administrative certificates to food service sanitation, the latter necessary when day care programs funded by the Department of Children and Family Services (DCFS) serve meals to children.

The actual coursework preparation for direct service staff as it relates to birth to 3 services is scant. The same holds true for administrators. When service providers were asked to indicate the number and title of specific courses related to infant programs or infants with special needs and their families, responses varied from "none" to listing a group of general curriculum courses that do not focus on topics relevant to provision of infant services. Only 5% of the courses reported taken were related to parents and parent-child relations. The diversity of courses identified as infant or infant-related courses cited by administrators were as varied as those cited by service delivery staff. Again, most were not related to infants nor to infant intervention.

In the Level II interviews, administrators indicated that they needed more qualified personnel. In addition, they suggested the need for university coursework for infant program personnel.

Staff development. Infant program staff seem to be so busy delivering services that there is little time left for staff development activities, although lipservice is paid to the concept. However, in one region of the State, the Region 1 Consortium of Birth to 3 Service Providers has solved the inservice problem by meeting monthly for training. The Consortium is a cooperative venture between county agencies and the Outreach: Macomb 0-3 Project. A similar consortium is operated in the Rockford area by Project RHISE and Birth to 3 service provision agencies. More staff members than we would like to report spend little or no time in inservice activities at a time when new knowledge comes into the field monthly. This means that staff with little or no specific work in infant programming may also be receiving little or no inservice to upgrade their skills. Administrators present a somewhat different picture than service delivery staff. They indicate that their staff participate in inservice from 15 to 17 times a year and that they (the administrators) are relatively satisfied with inservice programs.

Funding. By and large, staff members felt that birth to 3 intervention programs received loss than adequate funding, a condition which also contributed to signs of low morale. Some parents in Level II interviews echoed this view, indicating that programs must have more money.

The budget figures provided by administrators were so discrepant that they are indeed questionable. Yet, these figures provide a base for further research which is needed. Administrators report that the bulk of the funding comes from the Department of Mental Health and Developmental Disabilities (DMHDD), although a number of other funding sources are used.



Staff morale. The mean rating of attitude and morale of program staff on a scale of  $\overline{1}$  (low) to 5 (high) was 4.032, reflecting a relatively positive spirit. Low salary and no mobility were signs of low morale, but "good communication," "flexibility in working together as a team," and "professionalism" were frequently mentioned as causes of high morale.

# Recommended Standards

This section contains recommended standards for comprehensive birth to 3 early intervention programs. The standards were developed from information gathered in the review of the literature, the review of the exemplary model programs, examination of other states' early intervention programs and standards and Illinois' regulations for birth to 3 programs, contributions from members of the Advisory Panel, and information gathered through the use of the questionnaires and interviews. The Commission for the Accreditation of Rehabilitation Facilities (CARF) guidelines (1984), the Higher Education Advisory Committee (HEAC) recommended standards for personnel in birth to 3 programs (1984), the Macomb 0-3 Project's Model Fidelity Form (1984), TADS' Comprehensive Program Review (1983), Project RHISE/Outreach's Needs Assessment (1983), and Bricker's report from a working conference on birth to 3 personnel competencies (1984) were also used in compiling the recommended standards.

The standards given here are intended to provide guidance and direction. When it has been possible to provide specific procedures that can apply to any program in any circumstance, an attempt has been made to do so. Yet, recognizing that flexibility is the touchstone of early intervention services, many of the recommended standards are general, to allow for the differences in service delivery models, sizes of programs and number of staff, cultural and social milicu, and most of all, the special needs of each child and family.

A comprehensive early intervention program needs to provide specific services to the infants and families it serves. These services are usually addressed through program components. The components are necessary to implement and maintain an early intervention program for children with special needs and their families. Components of a program must include: 1) program structure, 2) identification, 3) eligibility determination, 4) program development, 5) program implementation, 6) transition, 7) evaluation, and 8) administration. Each component will consist of a number of activities through which the necessary services are accomplished.

Public Law 98-199 allocated federal monies in the form of grants which were awarded to each state's educational agency (or other responsible state agency). These grants were to assist in planning, developing, or implementing an Early Childhood State Plan for a comprehensive delivery system of special education and related services to handicapped children from birth to 5 years of age. The requirements which the states must meet in their comprehensive service delivery system plans may be found in Figure 1, page 2.

The components we designate as being necessary for a comprehensive delivery system comply with the guidelines for statewide systems provided in PL 98-199. However, we have chosen to arrange the components in chronological order, from initial identification of the child through her involvement with



the program to her transition to the public schools and termination of early intervention services. This arrangement facilitates inclusior of components of specific concern to individual programs and delineates more clearly the process involved. Issues of program organization and ongoing administrative concern are treated at the end of the chronological sequence.

# Components of a model program.

#### I. Program Structure

Goal: To establish an efficient and effective set of procedures necessary to allow the program to initiate service activities.

# A. Eligibility Criteria

- 1. The program should establish eligibility criteria which specify precisely types of handicapping conditions and at-risk categories to be served. It is important to be precise in specifying the degree of delay and disability and the areas of delay and disability that the program will serve. Ultimately, criteria rest on the laws and/or rules of regulatory agencies regarding services to the birth to 3 special needs population.
- 2. The eligibility criteria should include the geographical boundaries served by the program.

#### B. Cooperation with Appropriate Professionals

- 1. The early intervention program must cooperate with outside professionals in locating the children who may be served by the program, in evaluating children in the program, and in referring children to other appropriate agencies or individuals.
- 2. The program should establish formal agreements with other agencies and individuals. These should include, but need not be limited to, hospitals, clinics, social service and welfare agencies, other programs serving some or all of the same categories of children, medical personnel, educators and child development specialists, speech and language pathologists, nutritionists, physical and occupational therapists, psychologists, psychiatrists, and social workers.
- 3. Where needed, the program should have translators or bilingual specialists.

# C. Alternate Service Linkage

1. The program should develop files of agencies which provide services appropriate to children who are ineligible for its early intervention services.



- 2. Formal and reciprocal agreements should be made with each of those agencies.
- 3. The early intervention program should make provisions for linkage and follow-up to insure that the child receives the necessary service.

# D. Community Awareness

- 1. The program should develop a formal plan for informing the general public about the program.
- 2. The plan should attempt to reach every stratum of society and to explain what children are served by the program and how children can be referred to the program.

(Further administrative standards and guidelines are found in Part VIII of this chapter.)

#### II. Identification

Goal: to locate and identify, as early as possible, all birth to 3-year-old children who are handicapped or at-risk of being handicapped who reside within the geographical location served by the early intervention program. This will include the prenatal period if there is evidence that the child will be born handicapped.

#### A. Community Awareness

- 1. Implementing the plan for informing the public about the program should be an on-going process. Files should be kept and periodically updated on agency, organization, and media contacts, and the plan should be occasionally evaluated for its effectiveness.
- 2. A written agreement should be made with other programs serving some or all of the same categories of children within the same geographical area. This agreement should specify what population each agency serves and how referrals may be made from one program to another. It should also indicate how the agencies will work together to inform the public of available services and of the cooperation among agencies.

#### B. Newborn Registry

- 1. Newborn registries should be maintained or established with all the hospitals in the geographical area served by the program. These will be formal systems which insure that children born with or born at-risk for handicapping conditions are identified and referred by hospital staff (with parental consent) to the early intervention program for screening, monitoring, or both.
- 2. The newborn registry should be coordinated with the perinatal management and tracking system and the developmental disabilities tracking



system which the Department of Public Health has been mandated to develop under the "Baby Doe" legislation.

#### C. Referral Network

- 1. A formal referral network should be established to include all agencies, hospitals, and professionals who serve birth to 3 year old children. The network should hold periodic meetings. Information regarding each program and its services and how to refer children for services should be presented at the meetings. Trouble-shooting to identify problems with the referral system should also be done at the meetings. Information should be provided in writing to those unable to attend, and they should be asked to provide feedback about the referral system.
- 2. Written agreements should be \_eveloped between the program and the agencies in the network establishing a systematic referral process.
- 3. Any changes in the referral process should be made only after notice to the members of the referral network who would then be allowed to give feedback regarding the proposed changes.

# III. Eligibility Determination

Goal: to evaluate the child's current developmental status in order to determine whether the child is eligible for early intervention service.

#### A. Screening Process

- 1. A systematic screening process should be established in writing which includes the use of both formal and informal methods to determine whether the child appears to be eligible for services and needs further evaluation. These methods should include a) screening with a valid and reliable tool which is appropriate to the age and handicapping conditions of the child, b) reviewing her medical records and other agency records, c) conducting intake interviews with the family, and d) making observations of the child. Care should be taken to orient the parents to the process and to involve them in the process whenever possible.
- 2. An ongoing mass screening program should be implemented. This should include advertised screenings in several locations of the geographical area served by the early intervention program. Screenings should be scheduled for evenings and weekends, as well as during the working week. They should be planned on a yearly basis and advertised to the public throughout the year. The screenings should include visual screening and nutritional evaluation.
- 3. The screening process should be waived for children with an established biological risk or a significant developmental delay reported during intake. Those children should immediately be referred for evaluation.
- 4. A child need not be rescreened if screening reports from agencies and professionals within the referral network exist. The child should be referred immediately for evaluation.



- B. Borderline and Ineligible Children
- 1. Children who are borderline should be placed on a monitoring list and reevaluated at a later date, preferably within six months.
- 2. Children referred to the program who do not meet the eligibility criteria should receive additional evaluation to insure that every child's needs are met.
- 3. If at any point a child is deemed ineligible for service, the reasons should be explained to the parents. This decision should be documented in writing with copies given to parents and to the referral source.

#### C. Intake Process

- 1. An intake process should be established in writing. This should include identification data gathered from parents, medical records and relevant information from other agencies through which the child has received services, parent orientation procedures, parental consent, and screening procedures.
- 2. The application for enrollment in the program should request only information useful to understanding the nature of the child's developmental problems and the family's needs. A provision should be made to assist poor and non-readers in completing the application.
  - 3. Specific timelines should be established for the intake process.
- 4. Data should be kept on intakes including, but not limited to, reason for referral, age at time of referral, source of referral, time frames for various aspects of the intake process, and eligibility determination.
- 5. A medical diagnosis should be requested on each child. This may be done through the child's physician or through a consulting physician in collaboration with the child's physician. Ongoing communication with the child's physician should be maintained by support services.
- 6. Any referral should be acknowledged and the referral source should be notified of the results.
- 7. The family should be offered the option of having the initial interview in their home.
- 8. The intake process should be conducted in the parents' native language or through the use of a translator.
- 9. Parents should be told the results of the eligibility determination as soon as possible after the screening process. They should also be given a written statement regarding the child's eligibility or ineligibility for program services. If the child is ineligible, the reasons should also be explained to the parents in writing with a copy sent to the referral source.



10. Transportation should be provided to attend any appointments, screenings, and so on for those families who can not provide or find other transportation.

# D. Multidisciplinary Evaluation Process

- 1. The evaluation process should be conducted by a multidisciplinary team including the child's physician, developmental specialists, educators, speec. and language pathologists, audiologists, occupational therapists, physical therapists, psychologists, social workers, nurses, and the child's parents. All these professionals need not be a part of each child's evaluation. Each child's unique needs should determine which members of the team participate in the evaluation process for that child.
- 2. Appropriate and reliable tests and checklists should be used as part of the evaluation process. Observation of the child and the parent-child interaction should also play a role in the evaluation.
- 3. The following areas should be considered during the evaluation process:

parent-child relationship
child's temperament
child's learning style
speech/language development (communication skills)
social-emotional development
cognitive development
self-help skills (riaptive behavior)
sensory development
oral motor development
gross motor development
fine motor development
muscle tone
home environment
range of motion
health

Different tests and guidelines use slightly varying lists of areas to evaluate. For example, CARF guidelines for evaluation of the birth to 3 population include: sensorimotor skills, including fine and gross motor skills; interpersonal relations, including the family; cognitive functioning; communicative functioning; and affect and temperament.

Some of these factors should be evaluated through observation rather than by use of a formal instrument. If it is obvious that no problem exists in some of the areas, the child should not be evaluated in those areas.

- The child should be tested in his native language.
- 5. Adaptations should be made in test procedures to accommodate the handicapping conditions of the child if tests appropriate to the handicapping condition are not available.
- 6. Each child's growth (height and weight) should be assessed and monitored periodically while the child is enrolled in the program. Records



should be kept. If this is being done regularly by a physician or public health department, the early intervention program need not duplicate this assessment as long as it maintains a set of duplicate records.

7. At least a part of the evaluation process should be conducted in the child's home. The child's home environment should be included in the evaluation.

#### E. Parent Involvement

- 1. Parents should be oriented to the evaluation process. Parent involvement should be facilitated orally and in writing through the use of a brochure or a parent handbook.
- 2. Parents should be a part of the evaluation process and included in the formal evaluation sessions. Their input should be requested regarding the child's developmental functioning. Information from the parents is an important part of the evaluation.
- 3. Transportation should be provided to parents to enable them to attend the evaluations if they need transportation.

# IV. Program Development

Goal: to develop an individualized program for the provision of educational, developmental, therapeutic, and supportive services for the child and his family, based upon the results of the child's evaluation and an assessment of the family.

#### A. Curriculum

- 1. The intervention sessions should be planned taking into account young children's urgent physical, emotional and developmental needs. The realities of the child's needs for movement, security, and feelings of competency and mastery should be incorporated into the curriculum activities.
- 2. The curriculum should be based upon the unique handicapping conditions and needs of each individual child.
- 3. The primary goal of the program curriculum should be to develop healthy, appropriate parent-child interaction.
- 4. The readiness of the parent for involvement in the program should be considered part of the decision concerning what activities to include in the intervention sessions.
- 5. Insofar as possible, the curriculum activities should be taught to parents in such a way that they can integrate them easily into their daily child care and household routines.



- 6. The curriculum should be seen as a flexible process which the child engages in with the parent rather than activities that must be completed. This process should lend itself to teachable moments.
- 7. Toys, materials, and equipment should be available to loan to parents when appropriate to the development of the child.
- 8. Activities such as water play and outdoor games should be incorporated in the curriculum when possible.

# B. Individual Education Program

- 1. An Individual Education Program (IEP) should be developed for each child during the planning staffing. It should include:
  - a. a statement of the child's eligibility for program services;
  - b. documentation of the child's current level of functioning, including health and developmental status;
  - c. any need for further evaluation;
  - d. a statement of the child's and the ramily's strengths and needs;
  - e. goals and objectives for promoting the child's development;
  - f. goals and objectives for the parents;
  - g. specific intervention strategies to be utilized to meet the child's and the parents' needs;
  - h. intervention dates and the duration of the intervention program;
  - i. techniques and methods to be used;
  - j. specific staff involved;
  - k. other agencies involved;
  - 1. 3 description of the parents' role in the intervention
     process; and
  - m. goals for the parents' involvement in the early intervention strategies.
  - 2. Provision should be made for written progress reports.
- 3. Provision should be made for at least semiannual interdisciplinary review of each child's plan for services, goals, and progress toward goals. The review should be conducted by appropriate staff members.

# C. Multidisciplinary Decision

- 1. The IEP should be based upon the input of the multidisciplinary team which evaluated the child. Parents should be fully involved as members of the team. In some rare occasions it may be necessary to have the staff members conduct a preliminary staffing and have a member of the staff meet with the parents to review the tentative decisions and get parent input and feedback prior to finalizing the IEP.
- 2. Parents should be oriented prior to the staffing regarding the IEP rocess. They should be shown a copy of the IEP form.



- 3. Parents should be told that they can invite others to the staffing for support or to provide input in the decision making process.
- 4. Parent input should be actively sought during the staffing. All input, from both staff and parents, should be considered part of the recommendations to the team for consideration. It is recommended that a staff member serve as a parent advocate during the staffing asking for clarification and information on behalf of the parent.
- 5. Although all members of the teams should provide input, it is important to minimize the number of staff members at the first IEP staffing for the child.

#### V. Program Implementation

Goal: to provide appropriate educational, developmental, therapeutic, and support services to the child and his family based upon the Individual Education Program.

# A. Intervention Strategies

- 1. A variety of strategies should be available through each program. These should include in-home service, center-based service, or combinations of these. Opportunities for individual, small group (two to four children), and large group (five to eight children) service should be available through each program.
- 2. The needs of the child and family should determine the particular strategy which is chosen for each child.
- 3. The frequency and duration of service should be flexible depending upon the needs of the child and the family. Sessions should be available at least once a month to several times a week. The length of time of the sessions should range from 1/2 hour to 2 1/2 hours a day depending on the needs of the child and the family.
- 4. Play should be recognized as an important component of the intervention process.
- 5. Opportunities for mainstreaming 2- to 3-year-old children should be available through the program or by referral from the program. If this is accomplished by referral to another program, the two programs should work jointly while the child is enrolled in both, or the early intervention program should act as a consultant to the other program in which the child is enrolled exclusively.

## B. Parental Involvement

1. Intervention sessions should include parents in order to transfer knowledge and skills to them. Exceptions occur for example, when it is determined jointly by the primary staff person and the parent that the parent needs some time away from the child (this would generally be a time-limited



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decision) or when parents have needs which preclude their involvement in the program, although the long range goal should be to include them in the program.

- 2. All intervention activities should be planned with a recognition that parents, although they are considered the primary teachers of their children, are more than teachers. They have responsibilities for a household, other family members, a job, and their own mental and physical health.
- 3. Other family members should also be considered interventionists and included in the sessions as appropriate. These may be grandparents, siblings aunts, and uncles. Other significant caretakers of the child should be included in the intervention process when appropriate.
- 4. If parents are unable to be included on a fulltime basis in the intervention sessions, program staff should develop ways to keep them updated as to what is happening in the sessions and involved in intervention in the home, and to make them a part of the decision-making process. The telephone, notebooks or journals, written reports, and written lesson plans are means to include parents.

# C. Assessment of Progress

- 1. Each child's progress should be assessed at least every 6 months with valid, reliable instruments appropriate for the child's handicapping conditions and developmental level. Instruments used for this purpose are distinct from those used to determine ongoing activities.
- 2. Accurate records of the child's progress should be maintained, analyzed, and discussed with the child's family.
- 3. Curricular assessment for determining ongoing intervention should occur daily or weekly, but maximally at 2 month intervals.
- 4. Ongoing observation records describing the child's behavior, and environment if needed, should be noted after each intervention session. Records should be kept in the child's file.
- 5. Parental report records on the child's behavior should be noted by program staff and filed in the child's records.
- 6. A formal parent report regarding the child's progress should be completed at least at 6 month intervals on a systematic basis.

# D. Family Support

- 1. Intervention services should be provided to the parents, taking into account the facts that both the discovery that a child has special needs and the ongoing parenting of that child are stressful, time consuming and exhausting to the parents.
- 2. Parents should be offered home visits on a regular basis as part of the support process.



- 3. Parents should be offered opportunities for parent-to-parent contact as part of the support process.
- 4. Parents should be oriented to any transition within or from the early intervention program well ahead of the time of the actual change. They should be supported through this time of change and for a period of time after the change if necessary.
- 5. Parents should be offered opportunities for day care and other types of respite if such opportunities are not already available to them. These should be provided or facilitated by the program, or the parents should be referred to opportunities outside the program.
- 6. Parents should be offered the opportunity for participation in parent groups. These should include, but not be limited to, support groups, educational or informational groups, and social groups. They can be either formally organized or informal. They can be general groups or groups organized for particular interests or members—for example, couples, fathers, mothers, teen-aged parents, or parents of children with specific handicaps. These groups need not be formally sponsored by the program, but can sometimes be organized in cooperation with another agency in the community.
- 7. Counseling, including genetic counseling, should be available to parents through the program or by referral from the program. If by referral, there should be a formal agreement between the agency providing the counseling and the infant program.
  - 8. Sibling groups should also meet on a periodic basis.
- 9. Counseling should also be available for the siblings of the children served in the program, either by the program or through referral.
- 10. All families served by the program should be provided opportunities for informal social interaction through activities such as Christmas parties, picnics, potlucks, and outings.

#### VI. Transition

Goal: to insure an orderly, appropriate transfer from the early intervention program to other appropriate programs for the child and his family.

# A. Discharge Process

- 1. Each program should develop a carefully planned, systematic transition process which begins several months before the actual time for the child to leave the program, and takes into account the agreement regarding referral procedures with agencies to which the child might be referred.
  - 2. Interagency conferences should be conducted prior to the discharge.
- 3. A written report including the child's strengths and weaknesses, learning style and curriculum suggestions should accompany the child.



# B. Rights and Advocacy Training

- 1. Parents should be informed of their rights prior to the transition of their child from the program.
- 2. Parents should receive training in how to advocate for their child in the event that it should become necessary.

# C. Alternate Service Linkage

- 1. A formal referral network should be created to include possible placements for children when they are transferred from the early intervention program. These should include, but not be limited to, the public schools, Head Start, nursery schools, day care centers, day care homes, recreational centers, and park district programs.
- 2. Children should be allowed to remain in a program for a limited period of time after they have been referred to the new program to insure that they begin to receive service from that program. If this time period ends and the child is still not receiving services, the early intervention program should function as a case manager and advocate to insure that the child receives services or, if a program exists in the community which functions as an advocate for children and families, the child should be referred to that program.

# D. Follow-up Procedures

Each program should develop systematic follow-up procedures to make contact with the new agency after the child has been served by them for a period of time, and should document this contact and the outcome.

#### VII. Evaluation

Goal: to establish an efficient and effective set of procedures to insure systematic child evaluation, family evaluation and program evaluation.

- A. The program should establish and implement a written systematic set of procedures, including time frame, instruments, purpose, and responsible personnel, to evaluate children's progress. Written procedures and materials to analyze child progress data should be available for appropriate staff use.
- B. The program should establish and implement a written systematic set of procedures, including time frame, instruments, purpose and responsible personnel to evaluate family progress, skills knowledge, and satisfaction. Written procedures and materials to analyze the family evaluation data should be available for appropriate staff use.
- C. The program should establish and implement a written systematic set of program evaluation procedures, including identified components, time frame, measures or instruments, purpose, and responsible personnel. The procedures should provide an evaluation of the comprehensive services provided. Written



procedures and materials to analyze program evaluation elements should be available for use by designated staff.

D. Data resulting from the child progress evaluation, family evaluation, and program evaluation should be summarized at least annually and organized for presentation to families, boards, decision makers, and other agencies.

#### VIII. Administration

Goal: to provide effective and efficient coordination and management of the early intervention program activities.

# A. Program Policies and Procedures

- 1. The program should have a written statement of overall program goals and objectives, including philosophies regarding child development and learning.
- 2. The program should have flexibility built into its policies and procedures to insure a consideration of the unique needs of each child and family.
- 3. The program should have a written statement of its organizational structure and decision making process.
- 4. The program should have a written statement of its roles and responsibilities.
  - 5. The program should have a written statement for family involvement.
- 6. The program should have a written policy for involvement and collaboration with other agencies and programs.
- 7. The program should allocate time annually for program review by administration and direct service staff.
- 8. The administration and personnel should be able to articulate the goals and philosophy of the program.
- 9. The program goals and objectives should be reviewed and revised if necessary to reflect any shifts in program planning and development or changes in state and federal laws.
- 10. The procedures for providing informed consent, due process and assurance of confidentiality should be carried out as established; release of information forms should be utilized when needed.
- 11. A waiting list policy should be established when this is a legal option.
  - 12. Criteria for program placement should be established.



- 13. The program should function on a 12-month basis. Even if this means operating only part of the day or week during some parts of the year, the program should insure that children who need services will not be without them.
- 14. The program should have an appropriate discipline policy in writing which takes into account the developmental uniqueness of the birth to 3 age level.
- 15. The program should have a written policy for reporting child abuse or child neglect.
- 16. The program should develop a system for keeping informed of current research and literature in the areas associated with early intervention service.
- 17. The program should have a board of directors that reflects the community which it serves and includes two or more parents of children in or formerly in that early intervention program.
- 18. The program should establish goals and objectives which focus on performance and results of program services. This is to insure that quality of services, rather than quantity of services, is the focus of the program.

# B. Personnel

- 1. The program should develop written personnel policies which include hiring procedures and an affirmative action plan, minimum qualifications, licensure or certification requirements, a salary schedule with salary ranges for years of service and educational levels, fringe benefits, employee evaluation and supervision, discipline and grievances, termination procedures, employee development and training, job descriptions and organizational charting, personnel files, and merit pay.
- 2. Program personnel should be knowledgeable in the growth and development of young children birth to 3 years of age and recognize the basic principles of growth and development.
- 3. The program should establish an annual staff development plan based on assessment of staff competencies and needs. Release time should be allowed for staff development activities and monies should be allocated in the program's budget.
- 4. Basic assumptions that the program should accept in regard to personnel training programs include a) that personnel who work with handicapped and high risk children ages birth to 3 require information and skills different from personnel working with the 3 to 5 age group; b) that the focus on intervention for the birth to 3 population are the parents and family members; c) that intervention with infants and their families requires maturity and judgement, and thus training programs should provide opportunity for practical experiences; d) that intervention with infants and their families often requires coordination of many disciplines and agencies (Bricker, 1984).



5. The program should hold regularly scheduled staff meetings to insure coordination of program activities, opportunities for feedback to the administration regarding problems with policies and procedures, a time to discuss problems with specific cases; and support for staff members.

# C. Case Management

- 1. Each child and family should be formally assigned to one staff person who functions as their case manager.
  - 2. The program should initiate a system of regular case reviews.

## D. Funding and Budget

- 1. The program should use a proactive rather than a reactive budgeting process. This means that the budget is established to insure an appropriate, adequate projection of expenses for the number of children served.
- 2. The program should have a system to allow budget input from all levels of the program so that each staff member provides an estimate of the necessary funding for those areas of the budget directly affecting her.
  - 3. The program should keep appropriate financial records.
  - 4. The program should arrange for impartial annual audits.
- 5. The program should establish appropriate financial procedures to insure that funds are used in a controlled manner.
- 6. The program should compile regular financial statements indicating income and expenditures for the period just completed.

#### E. Annual Program Evaluation

- 1. There should be an evaluation of each program component at least annually, which includes feedback from management, staff, parents and other agencies who refer children to and receive referrals from the program.
- 2. The final evaluation and recommendations for program change should include input from representatives of the professional staff involved in providing services through the program.
- 3. The program evaluation should reflect the fact that the primary concern of early intervention programs is effectiveness rather than efficiency; new policies and procedures improving the efficiency of program services should not be implemented if they lower the quality of the services.
- 4. The statement of the program's purpose should be the standard for determining any changes in the policies and procedures of the program, to insure that services necessary to the program's purpose are not eliminated in the name of efficiency.



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5. The annual program evaluation should establish goals and objectives for the program for the next year, as well as measure progress toward that year's goals and objectives.

#### F. Communication

- 1. The program should develop a system to insure effective communication among the board, management, staff, parents, other social service agencies and professionals, and the community at large.
- 2. The program should establish and maintain a Policy and Procedures Manual. Each member of the staff should be provided with a copy and be updated with all changes, deletions, and additions to the Manual.

#### G. Facilities

- 1. The early intervention program should be housed in a barrier-free facility to insure accessability to the physically handicapped.
- 2. The program should make use of research related to environmental design and its impact on birth to 3 year old children, parents, and staff. This should be considered when decorating the interior of the program area, the staff office area, and the areas where the intervention sessions are held.
- 3. The areas where children and parents are served should be attractive and inviting.
- 4. Adequate, appropriate, attractive work space should be provided for the staff.
- 5. Private space and facilities should be available for counseling and assessment services.
- 6. Storage areas should be provided which insure that materials and equipment are stored in a safe and orderly fashion.
- 7. Safety and sanitation standards should be met for all areas of the facility.

## H. Long Range Planning

- 1. The program should establish a long-range (3- to 5-year) plan in which it will as ess needs, set goals and objectives, and establish strategies and activities for achieving those objectives; in subsequent annual re-examination of the plan, the program should identify strengths and needs and measure the progress made the previous year.
- 2. The development of the long range plan should include input from all levels of the staff to insure that decisions are not made on the basis of hierarchical position alone.



# I. Volunteer Program

- 1. The program should establish a volunteer program including recruitment, screening, implementation, and recognition phases to facilitate community involvement in the program.
- 2. Tasks, identified qualifications, expectation, responsibilities, and time frames for volunteers should be identified in writing.
- 3. A plan should be established and implemented for ongoing supervision and evaluation of the volunteers.

# J. Licensing Certification and Legal Concerns

- 1. The program should insure compliance with the requirements of all state or local licensing and certification regulations and with applicable laws. This includes confidentiality. Programs should insure that they meet or exceed these requirements.
- 2. Coverage should be provided for general liability and professional liability.
- 3. The program should take into account the unique developmental aspects of the birth to 3 age range when provisions for health considerations such as medical emergency planning, classroom sanitation, dispensing of medicines, nutritional requirements and physical management are made.
  - 4. Provisions should be made to insure confidentiality of records.
- 5. Procedures for evacuation of the building in the event of fire and for protection of the inhabitants in the event of tornado should be established and made known to staff members and volunteers. Drills in these procedures should be held regularly.
- 6. Procedures should be made to meet emergency situations such as child sickness or injury, snow storms, power failures, transportation breakdown, and staff shortages.

#### K. Community Relations

- 1. An annual community relations plan should be established to insure that all segments of the community are informed of the existence of the early intervention program, the types of services it provides, the children it serves, and how to refer children to the program.
- 2. Methods of implementing this plan should include the use of brochures, media presentations, speakers, newsletters, annual reports, open houses, and other appropriate materials and activities.

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# Recommendations

The recommendations which follow are based on the findings of the two level survey of Illinois birth to 3 programs accomplished in 1984; the reviews of early intervention literature, existing state standards, standards in other states, and practices in exemplary tirth to 3 model programs; and input at several levels from the Advisory Council for the study and from other interested professionals. The preceding section on standards also contains a number of recommendations targeted specifically at program components. Those standards are not repeated in this section.

First, we would note that there are many positive findings regarding birth to 3 programs in Illinois. Not only are the programs operational, but a small group of them have been in place for 10 years or longer. Many have been funded by the Department of Mental Health and Developmental Disabilities. Funding, though respondents believe it to be at a lower level than is actually needed, has been provided to birth to 3 programs on an ongoing basis. This ongoing funding demonstrates a willingness to support social services shown to be effective on a case-by-case basis, even though the research community had not fully accepted that effectiveness. Other states have not provided funding to birth to 3 services to the same extent as Illinois, in spite of the fact that its regulations and standards at the state level are relatively sparse.

Further, parents reported overwhelming satisfaction with birth to 3 services and see their children as making progress they would not have made without the programs. Program staff distributed survey instruments to parents to fill out, a factor which could produce a bias toward positive comments; however, in a similar study of the 3 to 5 population which used the same sampling procedure, parents reported dissatisfaction with the programs (Hutinger & Swartz, 1980a), a fact which suggests that opportunities for negative comments were present in the infant study. Because parents were not asked to put their names on the returns, they are not identifiable, nor are the names of parents who responded to Level II interviews identifiable. Anonymity was insured. We see their satisfaction as positive evidence that programs are serving families and children in appropriate ways in the parents' eyes.

Yet, we also found areas where birth to 3 programs in Illinois can be improved, at several levels. Some needs are immediate. The recommendations are focused on these areas. They are organized according to broad areas related to approach, standards, personnel certification, record-keeping, funding and budget, eligibility criteria, staff development, program evaluation, and program characteristics.

Approach. Given the necessary multidisciplinary character of tirm to 3 programs, a multidisciplinary approach should be incorporated in all aspects of birth to 3 programming from state level agency decision making, including standards and personnel certification, to the regional and local level of programs for children and families, staffing, and services offered.

Further, in keeping with the multidisciplinary approach and the variety of professionals and services involved, we recommend that, rather than a single agency being given administrative responsibility, a group of agencies form a consortium at the state level to establish policies and regulations, hold



administrative responsibility, appoint task forces to study issues of interest, and accomplish other tasks as needed. Minimally, the group should be composed of representatives of the following agencies: Department of Mental Health and Developmental Disabilities, Department of Public Health, Division of Services to Crippled Children, Department of Public Aid, and Illinois State Board of Education. Administrative responsibility for the quality of birth to 3 programs must be clearly defined. Ideally each agency would be responsible for the aspect of programming that corresponds to its areas of expertise, although one might be designated lead agency for practical purposes. We see no single agency as more important than another, given the need for the multidisciplinary team approach.

Since the Illinois State Board of Education (ISBE) has secured funding, through an Early Childhood State Planning Grant (ECSPG) from the U.S. Department of Education (Special Education Programs), for the specific purpose of planning for the development of services to handicapped young children (with emphasis on the birth to 3 population), agencies presently concerned about related issues should be invited to participate in ECSPG activities and work together to accomplish some of the activities recommended from the findings of the present study as they fit within the goals of the ECSPG. Cooperation among all the groups concerned with birth to 3 programs in Illinois can only benefit Illinois children and families.

Because the data compiled from this study clearly demonstrated that some groups of professionals tend not to talk to other groups, we recommend that state level agencies set up and implement a mechanism to encourage regular and open communication among all the professionals who work with young children. Physicians and other medical professionals need to communicate with service delivery personnel, and public health nurses need to talk with program staff. While these are only a few examples, we found enough information that was misunderstood by broad groups to recommend the establishment of accepted formal channels of open communication. Professionals from different systems need to learn each others' languages and systems and be informed of what others are doing. While this is probably best done informally at the local and regional level, there must be state level responsibility for such interaction.

Information collected in the study indicates that the degree of communication and cooperation presently existing between schools and birth to 3 programs (where schools do not operate the infant program) is less than should be expected. A concerted effort by both school administrators and birth to 3 administrators should be made to improve interactions between two, no matter what the final outcome of legislation happens to be.

The data from the high risk units indicated that personnel from those units are sometimes unfamiliar with opportunities for early intervention services for families when children leave the units. A mechanism for establishing open communication between high risk unit personnel and area infant programs is necessary, within reasonable time constraints.

Development of a set of standardized terms would enhance both clarity of communication and ease of family understanding. For example, there are at least three different labels for the Individualized Educational Program process. Use of standardized terms should be common procedure for the professionals who work with birth to 3 programs. Since schools use the term "Individual Education Program" to describe the plan for a handicapped child's



program, and since that term is used for the larger part of the child's school life, we recommend that the term "IEP" be used in all birth to 3 programs in Illinois, no matter what the programs' funding source happens to be. A study of terminology used by different professionals, and a concerted effort to clarify and make those terms consistent would be a great help to families who have to face a multitude of problems.

Standards. A task force representing the disciplines necessary for operating successful birth to 3 programs should be convened to study the standards proposed in this study, to revise them as needed, and to make final recommendations. No single group should be over-represented on this task force. For ease in explanation and a broad perspective on the results of the present study, one person from this study should sit on the task force. Representative parents should be included.

Given the significant differences in programming between rural and urban programs, we recommend that those differences be recognized and encouraged where they are positive. When standards are set for programs, attention should be paid to the unique characteristics of both rural and urban programs, and the strengths of both should be not only permitted, but encouraged. Rulings about the numbers and kinds of staff, for example (some may not be available in rural areas), should not place programs in jeopardy. Different service delivery models should be available, depending on the needs of families, communities, and the agencies housing the programs.

<u>Certification</u>. Considering the multidisciplinary nature of infant programming and accompanying staff, we recommend that a group of certificates reflecting appropriate training in infant program content be accepted for infant personnel, rather than any single certificate. Acceptance of similar qualifications across agencies should be a factor in maintaining strong programs as we face a transition time prior to, during, and after attempts to legislate a birth to 3 mandate in Illinois.

Before state certification standards are finalized, a multidisciplinary task force of birth to 3 professionals and trainers should review the standards which have been recommended to the ISBE by their Higher Education Advisory Committee. The task force should also review certification standards for infant personnel from other states and from training programs in Illinois and across the country and make final recommendations. The task force should include service providers, program administrators, trainers, and parents. The issue of the qualifications of service delivery personnel is too important to be left to a single group. All regulatory agencies should be involved and finally agree on final standards.

A set of performance competencies which should be demonstrated by infant personnel and which take into account the wide ranges of tasks accomplished by various disciplines as well as the different levels of service providers (from aide to lead infant development specialist or administrator) should be developed, field tested, and implemented on a state-wide basis. Such competencies already exist in Illinois in at least two locations. A comprehensive field study should be funded at a level that would provide adequate resources to accomplish the task within a minimum time period of 2 years.



Record-keeping. Using the list of comprehensive birth to 3 programs identified in the present study, an accurate listing with periodic updates of what services are available within the state is recommended. A data base system on a small computer could be used to collect and disseminate the information either by modem (using a bulletin board format) or with hardcopy. Past criticisms of directories basically have argued that by the time a directory is printed it is out of date. With access to computer technology, the criticism is unfounded. A mechanism for updating the information should be developed. Funding to accomplish this activity should include resources for data collection, personnel, and telephone usage, as well as computer hardware and software.

Modification of the computer programs used for record-keeping by present agencies is recommended so that data specifically collected from comprehensive birth to 3 programs is easily available. Accurate information on infant services provided by Illinois agencies would include breakdowns of budget information, demographic data on staff and children, child progress information, and the number and types of handicapping conditions.

Funding. During and after the period when issues surrounding responsibility for birth to 3 services and accompanying legislation are discussed and reconciled, funding must not be lost by programs now operational. Agencies presently providing funds should continue funding programs. No program should lose funding as a result of current conditions related to control of birth to 3 programs in Illinois.

Birth to 3 programs in Illinois must have a stable, ongoing, adequate funding source. Programs must not be placed in a position of not knowing from year to year whether they will or will not receive funding.

Strategies to increase the funding of birth to 3 programs should be examined and implemented in order to increase the amount of money available to operate programs.

A mechanism must be devised that insures that funding earmarked for birth to 3 programs actually funnels into those programs. Agencies must not be allowed to channel birth to 3 funds to other purposes. The accounting system required by funding sources must take this into account.

Even though administrators call for trained, qualified staff, salaries in infant programs are often low, which causes low morale among direct service staff and accounts for fast turnover in personnel. Funding must be available to bring infant service delivery personnel salaries to a level commensurate with their training. Infant program salaries should be competitive with those of other employers in comparable fields.

Since the budget information collected in the present study represents such a wide range and is therefore highly questionable in accuracy, a carefully designed study, in which agency administrators agree to participate, should be funded to collect accurate budget information necessary to determine the present cost per child for infant programs in Illinois. The study should also be designed to collect detailed information about specific activities and services offered by infant programs. This study was funded to describe Illinois programs. Precise data on funding levels, cost per child, and



numbers of children served classified by handicapping condition would have been useful. Compiling this data was beyond the scope of the study, but the data is still needed.

Eligibility criteria. Given the positive data regarding the effects of early intervention on at-risk children, a broad interpretation of eligibility for services is recommended. Children demonstrating mild, moderate and severe handicaps (including children defined as "at-risk" or "high risk"), as well as their families, should be served by infant programs.

A uniform set of criteria for eligibility for receiving services is necessary. Agencies must work cooperatively to provide the services which are most appropriate to each child's circumstances in order to avoid costly duplication of services and harmful competition for the child. Such cooperation would be encouraged in areas where more than one agency exists.

Families should be allowed to receive services from the program closest to them. Current DMHDD regulations sometimes require families to travel some distance for services from a program within their service area, rather than to attend a nearby program within a different service area. This should not occur. It is too costly, and it places uncalled-for hardships on the family. Birth to 3 services should be available in all Illinois counties, and proximity should dictate where families go for services.

Staff development. In most parts of Illinois the skills of service delivery personnel must be systematically upgraded, beginning immediately. The immediate needs are best served by mounting inservice programs with some funding to trainers (i.e., for transportation and materials) and with funding for release time to service providers. Program services to families should not suffer because staff are taking inservice training. Systematic high quality inservice training should be offered to all Illinois programs immediately. Programs should have responsibility to insure that their staff participate in such inservice training.

Regional consortia, which meet monthly for purposes of inservice training (and addressing other objectives as recessary) should be established. Present DMHDD regions might be used, since that is a familiar grouping and will probably continue to be applicable for an unspecified time period as attempts to establish birth to 3 legislation are made. The Region I 0-3 Service Providers Consortium, operational for the past three years, can be used as a model across the state. Data clearly show that this consortium has an effect on the training of staff.

Inservice training can be immediately accomplished by using the resources available in Illinois and identified in this study. These resources already have training programs and workshops developed, as well as the expertise and personnel dollars for trainers at the present time. There is no need to reinvent training content or formats. These resources include the two functioning infant HCEEP Outreach Projects in Macomb and Rockford, the Illinois Institute for Developmental Disabilities, and isolated university programs.



The two training modules provided by this project focus on two topics identified as real needs by survey results. These modules are related to working with families and should be used to initiate training on a statewide level as soon as they are duplicated for distribution.

The topics that should be addressed first by inservice programs, in addition to those addressed in the modules, are those for which the Illinois study showed there is the greatest need: appropriate screening and assessment of infants and families; appropriate curricular content; strategies for demonstrating program effectiveness; strategies for documenting child progress or change; techniques for assessing family readiness, satisfaction with the programs, and parent skills; and techniques for multidisciplinary approaches, including learning about the language, systems, and approaches used by other professionals. Secondary topics are also addressed in the study.

A training materials center should be funded to collect available materials from Illinois groups, to examine other training materials from birth to 3 programs around the country, and to reproduce them for use in training. Across our state and the United States a wide variety of quality training materials has been developed. We do not believe that new materials need to be developed in most instances. Instead, we recommend the packaging of existing materials in a modular format to meet training needs in Illinois. We do not believe that individual programs should be expected to assume the costs of purchasing these materials, and we recommend a state source of funding and dissemination. Priority for materials acquisition should reflect the findings of this study, and it should represent both urban and rural programs.

When those who are responsible, decision-making infant personnel have no formal coursework in infant programming and related topics and report no systematic inservice attendance in the past year nor evidence of other training (such as HCEEP Outreach training in replication sites), requirements for developing and implementing immediate individual training plans should be established. The set of infant personnel competencies, possibly in draft form, recommended elsewhere in this section could be used to help personnel and administrators accomplish this task.

Formal university or community college training is not the only way, nor even the most desirable way, to upgrade service staff skills; however, these institutions must make and implement plans for developing appropriate coursework (keeping in mind the multidisciplinary approach recommended). Courses should be taught by faculty with experience in programming for handicapped infants and toddlers and their families. Faculty from a single department must not be totally responsible for teaching all courses. Faculty with experience limited to typical or nonhandicapped children must gain expertise in work with handicapped infants before teaching such courses. A task force of university and community college personnel, birth to 3 administrators and service delivery staff, and parents of children in programs should convene quarterly to plan and develop appropriate training projects at the undergraduate and graduate levels. While the training should not be duplicated, it should be available to all geographic areas of the state.

Birth to 3 personnel must have a mechanism to acquire new knowledge emerging in the field. A yearly state-wide conference or symposium, funded by the state agencies with birth to 3 responsibilities, should be held to update service delivery personnel on new knowledge and skills. This conference



should make use of the wide range of resources in the state from several different disciplines including medicine, public health, training projects (including HCEEP Outreach Projects and university infant personnel projects as they are funded), education, representative parents, service delivery staff and parents. We recommend that such a conference be held in a location close to the center of the state.

A technical assistance network should be established, composed of resources available in Illinois, to provide consultation to individual programs or groups of programs, using the regional consortia as the organizational structure for receiving services. A single agency ought not be funded to accomplish this task. Rather, in keeping with the multidisciplinary nature of infant programming, a consortium of training agencies should serve as consultants. The precedent has been set through the technical assistance provided by the First Chance Consortium. One agency might play the lead-role, but several should cooperate in this venture, making use of the unique resources of each geographical area. Consultants should be able to play a variety of roles, including offering coursework, inservice training, and individual or small group consultation.

Program evaluation. Programs should be required to collect specified data to show that they make positive differences in the lives of children and their families.

After standards are agreed upon, they should be organized in a format so that each birth to 3 program could do a self study, using the standards as a guideline, on a yearly basis with input from staff and consumers. External program review procedures should also be developed and implemented to accompany the new standards.

Evaluation data, demonstrating selected aspects of the programs' effectiveness, should be collected by the programs to meet the standards that are adopted. Inservice training on program evaluation should be provided to all program administrators and staff.

Child change data, based on use of appropriate valid and reliable instruments (not program developed instruments), must be maintained in each program. Inservice training to help programs establish effective data collection techniques should be provided at the regional consortia level. Consultants who could work with single programs or groups of programs should be available to help establish acceptable data collection procedures and to train personnel to auminister assessment instruments, if necessary.

<u>Program characteristics</u>. Waiting lists should be eliminated in all instances. Urban programs need to shorten the amount of time between referrals and the time children receive services.

Systematic procedures to assess both family needs and the impact of the program on families should be adopted.

In areas where programs are operating with inadequate facilities (too little space, not enough equipment), opportunities for securing funds to



upgrade facilities should be made available to programs that develop appropriate plans for doing so.

Transition from birth to 3 programs to public school programs should be improved. Formal transition plans must be adopted by birth to 3 programs and public schools together, in cooperation, until proposed legislation is acted upon. Those plans must be operational. Transferred records must not be lost. Although formal plans are important, we recommend formation of local transition committees to work together in face-to-face contact to increase the probability that those professionals involved in the transition process know one another and are therefore more likely to implement effective transition practices.

Suggestions for further analysis. Further analyses of the data collected in the Levels I and II are needed. Statistical analysis of selected items among groups, further comparisons between Level I and II results on selected items, and analyses of items in terms of program characteristics are needed. For example, comparisons among the groups on reported elapsed time from referral until services are obtained would be useful. The distance families travel to receive services should be analyzed in terms of both geographic area and the number of times they travel in a specific time period to receive services. Further analysis of the real-ideal dimensions on program components is needed. A careful content analysis of selected items, with accompanying statistical analysis where appropriate, would provide important information on open-ended items. Another analysis of selected items based on program characteristics such as number of children served or staff satisfaction would also provide useful information. Additional comparisons between results of the 1980 Illinois preschool study finaings and the findings of the present study would be valuable. These analyses were not accomplished in the present study because resources were not available to do so within the budget constraints of the projects and the comprehensive workscope. Further study of the findings related to the issues facing state agencies as they develop policies and procedures for birth to 3 services and examine legislative barriers would be helpful. Potential uses of the study as it relates to the model project concept now under consideration at the state level should be studied.

While the open-ended format used in questionnaires and interviews provided a wide range of data, suitable for exploratory purposes, we recommend that further work be conducted with forced-choice answers. Results of this study provide the basis for devising choices for respondents. We recommend that a second flight of revised Level I questionnaires be sent to a random sample of sites in 1985 to confirm Level I results. Careful and persistent follow-up to insure a high level of response would increase the validity of the present results. More precise data about budgets, handicapping conditions, curricular issues, and specific services could be obtained with a relatively low expenditure of resources.



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