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ABSTRACT

This "feature issue" focuses on early intervention with handicapped children, with an emphasis on: Project EDGE (Expanding Developmental Growth through Education), an early intervention research project initiated in 1968; strategies for developing family-friendly early intervention services; and progress reports from various states and programs. Individual articles include the following titles and authors: "Project EDGE: Early Intervention Pioneers" (John E. Rynders); "20 Years Later--EDGE Graduate Profile" (Susan Johnson); "Essential Features for Early Intervention Programs in the 1990's" (Diane Bricker); "The Key to Effective Early Intervention Services: Family Involvement" (Maria Anderson); "Family-Centered Intervention: Issues and Opportunities" (Jean Ann Summers); "Early Intervention: One Family's Experiences" (Susan Johnson); "IFSPs (Individual Family Service Plans): Implications for Implementation" (Carla Peterson); "Early Intervention and Least Restrictive Environment" (Samuel L. Odom and Mary A. McEvoy); "Social Integration in Action" (Scott McConnell); and "Mastery Behaviors: Motivation for Young Children with Developmental Delays" (Susan Hupp). Also included are progress reports from Minnesota, Iowa, North Dakota, and South Dakota as well as brief descriptions of some Minnesota early intervention programs. (DB)

INSTITUTE ON COMMUNITY INTEGRATION

IMPACT

Feature Issue on Early Intervention

Volume 2(2) Summer, 1989

Jerry Haley and his son Luke have experienced progress and frustration in seeking quality early intervention services. The family shares their story on page 10.

Early Intervention: New Options, New Hope

In the past decade, we have seen a number of changes at the societal level that have resulted in professionals modifying their ideas as to how to most effectively meet the needs of young children with handicaps. Parents, teachers, and other advocates interested in early intervention have seen an expansion in federal and state mandates. This expansion has included the Education of All Handicapped Children Amendments Act of 1986, which for the first time revealed the federal government's plans to mandate special education and related services for children between the ages of three and five. The Act also provided an incentive to states to develop programs for children with handicaps *and their families* from birth. We've witnessed incredible growth in the range of services available to young children with handicaps and their families, and there's every indication that this growth is going to continue. At the same time, researchers also have increased their attention to early intervention, resulting in a dramatic expansion in applied research on development, assessment, and intervention for preschoolers who have or are at risk for developmental disabilities.

These changes, and the realization that the family is the central milieu within which child development occurs, have led many professionals in the field to increasingly stress the importance of family-based intervention. We are now aware that if our goal is to facilitate the development of a child's competence, we must take into consideration the total context within which the family and child exist.

This issue of *IMPACT* highlights some of the exciting developments in early intervention. It includes a look back at Project EDGE, a pioneering early intervention research project initiated in 1968. EDGE had a profound impact on the lives of many children and their families, and the outcome of one such life is shared in the article on Holly Colwell, who graduated from high school this past spring. The issue contains stories of other families and their struggles to obtain quality early intervention services for their children. Strategies for developing family-friendly early intervention services and for promoting social integration in preschool programs are explored in several articles by nationally recognized experts. And, progress reports from several states and programs are shared.

This is an exciting time for young children with handicaps and their families...and it's an exciting time for everyone involved in the field of special education. As this issue of *IMPACT* demonstrates, we're surrounded by practitioners, parents, and researchers who have valuable insights into the strengths and weaknesses of current efforts and the major issues that must be considered in developing and implementing future family-based early intervention programs. Through sharing our experiences we can continue to create more effective approaches to early intervention, offering new options and new hope to children with handicaps and their families. •

-- The Editors

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A report from the Institute on Community Integration, University of Minnesota. **Dedicated to improving community services and social support for persons with developmental disabilities and their families.**

Project EDGE: Early Intervention Pioneers

by John E. Rynders

The year 1968 was, to say the least, an interesting one for Joe and Marsha Foster. Joe's career as a science teacher was receiving a big boost as NASA prepared to launch its moon landing mission. Marsha, a surgeon, was also doing very well professionally, though she looked forward to scaling down her medical practice as she planned for the birth of their first child. Both Joe and Marsha dreamed a lot. Mostly, they dreamed about how their child would grow up to become a scientist or physician (or maybe an astronaut). To these two people the future could not have looked any rosier!

> ***"...every time an early education program is successful with children who have Down syndrome, the developmental horizons of people with all types of mental retardation are broadened."***

Before the end of 1968 everything changed for the Fosters. Everything. On November 12th, Julie was born with Down syndrome. On that date, Joe and Marsha realized vividly that all of the incredible scientific and medical knowledge in the world, and the exotic technology that had been used to put two people on the moon, could not remove the one small extra chromosome that was in each of Julie's cells! During the next few days they were on an emotional roller coaster. The lowest point was when their physician said, "The best thing you can do for Julie and yourselves is to put her in an institution. She will always be like a baby. Maybe she won't even walk or talk."

Of course, this forecast was far too pessimistic but, in fairness to Julie's physician, information about Down syndrome was scant 20 years ago. In spite of all the advances since that time, however, parents' primary problem continues to be low expectations. Suffice it to say that in Julie Foster's year of birth little was expected of people with Down syndrome, so little was done to enhance their development.

Down syndrome, as the most prevalent clinical type of mental retardation and one that is readily recognized by the general public, serves as the reference point for professionals attempting to improve services for people with all forms of mental retardation. In fact, when a new educational technique or vocational program is developed for people with intellectual disabilities, the question that is likely to quickly arise among potential consumers is, "Yes, it looks good; but has it been used successfully with people who have Down syndrome?" Hence, in a real sense, every time an early education program is successful with children who have Down syndrome, the developmental horizons of people with all types of mental retardation are broadened.

The Birth and Growth of EDGE

In 1968, I and my colleague, Dr. J. Margaret Horrobin, a pediatrician in the University of Minnesota Medical School, received a five-year federal research grant to study the possible benefits of early family-based education for infants with Down syndrome. The project, called EDGE (Expanding Developmental Growth through Education), contained two groups of infants: an experimental group in the Twin Cities that received a linguistically-based play program, and a contrast (control) group in Chicago that did not receive EDGE's curriculum but instead received whatever programs had been chosen for each child (Illinois had state-funded early education programs in 1968). Across a two-year enrollment period, 20 families became part of the experimental group and 22 entered the contrast group.

In the experimental condition, parents received a set of simple objects and toys and were shown how to play with their child in a manner that promoted language development. For example, as Marsha presented Julie with the bubble soap and straws activity she had a lesson plan beside her that described several ways to make the activity interesting, interactive and rich with developmentally-appropriate vocabulary content. Play sessions were introduced at times that suited Marsha's schedule, and her efforts were supported by an EDGE staff member who dropped by the Foster's home on a regular basis. When Julie became 18 months of age, EDGE activities took greater advantage of her increasing mobility and language ability. At this time, Marsha received a new set of play lessons that paired each of the 20 original objects and toys, creating about 400 new lessons. This represented an attempt to capitalize on the motivating possibilities inherent in relative novelty without losing the foundational receptive vocabulary already established. Now, for example, the bubble soap and straws activity was combined with the doll activity so that the doll could become a bubble blower , too. And, it was combined with a set of child-size blocks so that bubbles could be blown out of the "windows" of the block "house".

When Julie and the other EDGE children in the experimental group became 30 months of age, they entered a community preschool program in Minneapolis. Providing a full range of nursery school activities, the emphasis on language development through language-oriented play continued until the children reached five years of age. At that point, they entered whatever educational programs their local school districts provided.

Periodic assessments were made of each child's cognitive, language and motor development until five years of age. At that age the program's effectiveness was evaluated. Results showed that children in the experimental group were significantly more advanced in their intellectual and gross motor abilities, but not in either their receptive or expressive language scores--the critical scores for judging the project's success since language was the undergirding emphasis throughout the entire five years of activity. Thus, we concluded that the EDGE findings did not support the language-oriented curriculum we had developed, but

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20 Years Later...

EDGE Graduate Profile

Twenty years ago there were no early intervention support systems available to most parents of children with handicaps, according to David and Char Colwell. In 1969, when their daughter Holly was born with Down syndrome, the Colwells talked with family members and other parents of children with Down syndrome in an effort to find resources and programs to facilitate her development. They heard about vitamin programs and Doman-Delacato procedures that were popular at the time. Their doctor asked if they had thought about institutionalizing Holly. A co-worker of David's then mentioned an advertisement on Project EDGE that appeared in the newsletter of the Association for Retarded Citizens. David recalls that "it took us 20 seconds to call and find out about the project." Holly was enrolled in Project EDGE when she was six months old.

The Colwells believe that EDGE opened doors for them and other parents who wanted their children in early education programs at a time when it was questionable whether such children would be accepted in most early childhood settings. The program provided Holly and her parents with activities similar to those in regular early education programs of the time. It also offered the much needed parental support. "We had our own built-in support system with the other parents in the project", according to Char. That system still operates today as many of the families continue to be in touch with each other. The project also provided them with answers to questions about their daughter from experts in the field of Down syndrome.

Project EDGE was beneficial to Holly both academically and socially. Her mother notes that Holly "thrived on academics" throughout school and that "something had to have been established really early for her as far as academics." Facilitating the development of basic social skills was possibly the greatest benefit of EDGE to Holly, according to her father. It's his belief that perhaps the specific techniques used were not as important as the opportunities for interaction between parents and their child and between children.

The Colwells see in Holly, and in other EDGE graduates, additional positive results of their involvement in the project. Its focus promoted teaching the children "how-to-do" and "how-to-grow", rather than emphasizing the negative--what the child was not expected to accomplish. EDGE facilitated parents giving their children opportunities to fail and to stretch their limits, promoting growth through such experiences. In the family's opinion, many of the children in the project have disproved the predictions and recommendations of the "experts" of 20 years ago.

David and Char extended their involvement in EDGE to benefit other parents of children with Down syndrome. When a child with Down syndrome was born in their area, often the friends or doctor of the new parents would contact David and Char, who would go to the hospital and visit with the parents. They were able to share what they had learned from EDGE and the competencies their daughter had developed. This type of information was not available to them when Holly was born, and they believed it was valuable information that should be available to other parents in similar circumstances.

Holly recently had a second graduation, this time from her high school. She was mainstreamed throughout her years in school, and her parents have no doubts that this was the right decision. Her classmates have viewed her as a peer; in fact, Holly reports that one of her favorite activities outside of class has been talking with her friends in the hallways.

Holly has a variety of interests. She spends much of her free time figure skating; she won a gold medal at the Minnesota Winter Special Olympics, and a silver medal at the International Winter Special Olympics held this year in Reno Nevada. Despite her busy schedule, she also finds time to go out to eat, to movies, to bowl, and to shop with friends.

Holly is happy to be leaving high school and moving on to new challenges. She's presently working at a snack bar. This fall, she plans to attend a technical institute. She will participate in an assessment program during the summer to help her select a course of study; she likes to cook and thinks that may be an area to look into. Her plans for the future include living at home while attending school, and then moving into a more independent living situation after she's settled in a job.

Twenty years ago, Project EDGE offered much needed information and support to the Colwells and other families; it also expanded the horizons for children with Down syndrome by offering a more optimistic view of what they could be expected to accomplish. As early intervention services continue to improve, there will be even more young people like Holly living, learning, working and sharing friendship as members of our communities. •

The Colwells were interviewed by Susan Johnson, Graduate Research Assistant in the Institute on Community Integration, University of Minnesota.

Essential Features for Early Intervention Programs in the 1990's

by Diane Bricker

Since the inception of formal approaches to early intervention in the 1970's, the field has made significant progress toward development of quality services for children who are at-risk or have handicaps, and their families. Much has changed in the ensuing two decades following a shaky beginning characterized by uncertainty in our approach and by a lack of the knowledge and experience needed to create fundamentally sound programs. As we enter the 1990's, an accounting of the field indicates significant progress. Early intervention now has a rich experiential and research base that provides a sound foundation for intervention approaches. In addition, there now exists a small but growing cadre of specially trained early intervention professionals. We have even come to recognize the importance of legitimate family involvement. All of these changes have been possible, in large measure, because of the passage of federal legislation requiring social accountability for even the youngest handicapped citizens. These reflections on progress bring feelings of satisfaction, particularly to those of us long associated with the field of early intervention; however, perhaps more importantly, these reflections offer a beginning point to speculate about future directions. The purpose of this article is to suggest three areas that are, or will become, essential features of early intervention programs of the 1990's.

Linking Assessment, Intervention and Evaluation

I believe early intervention programs are in need of a guiding theory that will enhance current intervention efforts with children and families. Often, programs seem to be omni-oriented--that is, they do everything for everyone, or at least as much as program resources permit. The alternative is to develop more theoretically sound approaches or models that provide a rationale and logic for what we do and why we do it.

In my view, one of the better prospects available for the development of more effective and efficient models is the direct linking of assessment, intervention and evaluation--a practice not currently found in most early intervention programs. This approach becomes even more exciting and viable if the directly linked assessment, intervention, and evaluation procedures are driven by the program's philosophy and goals. In such an approach, measures and procedures adopted for assessment directly reflect the program's emphasis and goals. For example, if the program emphasis is on the development of social skills, and a goal is to enhance mother-child interaction, this emphasis and goal should generate information on the child's social skills that leads directly to the development of an appropriate IEP or IFSP. In turn, the focus of intervention should be on the development of social skills. The intervention content is guided by the IEP or IFSP, and thus a direct link between assessment and intervention is forged. Ongoing evaluation should follow intervention and focus on the effectiveness of that intervention. In the present example, the focus of intervention is on social skills, and the evaluation focus should be on delineating the child's progress toward the acquisition of IEP or IFSP social skills goals and objectives. The systematic linking of program goals, assessment, intervention, and evaluation efforts appears to me to be an essential feature of early intervention programs that will be state-of-the-art in the 1990's.

Mainstreaming or Integration

The often emotional cry for placement of children with disabilities into schools and community-based programs for nonhandicapped populations, as opposed to placement in segregated, isolated programs, is not new. Although the practices of mainstreaming, integration, and reverse mainstreaming are defined in a variety of ways, the idea is generally to place children with and without handicaps together, so that both groups benefit. Most early interventionists support the philosophy of placing children with handicaps in programs where they have exposure to children without handicaps and thus more "normalized environments." The difficulty lies in the appropriate and beneficial actualization of that philosophy, as public education programs often do not exist for children without handicaps below kindergarten level. The typical environment for many infants and children below school age is daycare, making this a likely option for mainstreaming children with handicaps.

I believe that a second essential feature of quality early intervention programs of the 1990's will be their association with community-based programs for nonhandicapped young children. Early intervention personnel, daycare providers, preschool teachers, and parents working together will develop a variety of options for placement of children with handicaps where they can interact with broad and diverse populations of children. Placement of children with handicaps in community programs, particularly daycare, is currently of great concern considering the quality of services and the lack of personnel trained with special needs children. The challenge of mainstreaming infants and young children with handicaps is to assure that they receive the quality services necessary to enhance their development, while at the same time offering them the opportunity to interact with their peers.

Program Evaluation

The third essential feature of quality early intervention programs for the 1990's is the development and implementation of program evaluation procedures. These procedures will need to be practical and the outcomes meaningful and useful. Practical procedures are evaluation strategies that can be carried out, in large measure, by the intervention staff who operate the program. Most early intervention programs do not have the resources to hire extra staff to collect evaluation information, nor do they have the resources to hire specialists to administer

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tests that require extensive training and subsequent certification. The procedures adopted should instead be understood and usable by the staff in ways that are not overly disruptive to the program's operation. This does not mean that evaluation data are not collected, or are collected in unreliable ways. Program directors must find ways to integrate the collection of meaningful evaluation data into the daily and weekly activities of the program.

By "meaningful outcomes" I mean that we need to move away from reporting changes in test scores that may be interpretable only to the personnel who have collected the information and the analyst who has computed the outcomes. We need to collect information on program impact on children, families, and communities that makes sense to the audience when reported or shared. We need to talk in terms of child and family progress toward understandable goals, as opposed to shifts of numbers on pretest-postest scales.

Perhaps most important is that evaluation data should be useful to the staff who collect it and to the audiences for whom it is intended (e.g., parents and funding sources). If staff and parents are asked to gather or provide information, it should be obvious how the information will be useful. Collecting systematic data on a child's progress toward the acquisition of IEP goals selected by parents and staff should be of interest and use to both parties. Collecting information on the family's impressions of the usefulness of offered program activities should be of assistance to the staff. Before collecting any evaluation data, the staff should ask what purpose it will serve and if the investment of time and resources will yield useful information.

I believe that the reluctance of early interventionists to put sound evaluation plans in place is primarily a function of attempting to adopt traditional experimental procedures that generally are not appropriate for early intervention programs with modest budgets and little access to other resources (e.g., university personnel). Because meeting the specification of traditional evaluation designs has not been possible, many early intervention programs have conducted little or no program evaluation. In the 1990's, quality programs must plan and execute evaluation procedures that are practical and yield outcomes that are useful and meaningful to interventionists, parents, and other interested audiences.

The 1990's present early interventionists with the significant challenge of expanding and improving services for young children who are at-risk or who have handicaps, and their families. I believe fundamental for program improvement are the adoption of features that link assessment, intervention and evaluation, that provide mainstream options and that permit useful evaluation.

Dr. Diane Bricker is Professor of Special Education and Rehabilitation, and Director of the Early Intervention Program, in the Center on Human Development, University of Oregon.

The Foundation for the Future: Summary of Early Intervention Legislation

- **The Education of All Handicapped Children Act of 1975 (PL 94-142).**

This Act of Congress asserts the basic rights of school-age children with handicaps to receive a free, appropriate public education. It outlines the procedures that must be followed by representatives of school systems to ensure these rights and requires state and local education systems to provide special education and related services.

- **The Education of All Handicapped Children Amendments Act of 1986 (PL 99-457).**

This Act of Congress is a downward extension of the Education of All Handicapped Children Act. It ensures a free, appropriate public education for all three to five year old children with handicapping conditions by the 1990-1991 school year. This makes mandatory those special education programs for three to five year olds that were optional under the original version of the Education of All Handicapped Children Act. In addition, the Amendments Act of 1986 established a state grant program that provides funding for training, research and demonstration projects and offers incentives to states to provide special services to preschool children with handicaps prior to their becoming mandatory in 1990.

- **Part H: The Education of All Handicapped Children Amendments Act of 1986 (PL 99-457).**

This section of the Amendments Act authorizes incentives for the development of early intervention programs for children with handicaps from birth to three years of age who are either at risk for delays or have been determined to be delayed in cognitive, physical, language, speech, psychosocial or self-help skills. Financing has been made available to aid states in developing statewide, multidisciplinary, early intervention programs for infants and toddlers and to establish Interagency Coordinating Councils to oversee early intervention services on a statewide basis. In addition, this law mandates the establishment of Individualized Family Service Plans (IFSP) for each child and family in need of services. •

Progress Reports

Minnesota

Implementing the Birth Mandate

by Sandra Fink

On July 1, 1988, Minnesota joined the states of Iowa, Nebraska, Maryland, and Michigan in having a state mandate to serve children with disabilities from birth. Prior to implementation of the mandate, 50% of the school districts in Minnesota were serving at least one child under the age of three. The state child count for children birth through two years of age in early childhood programs has nearly doubled from December, 1987, to December, 1988, following passage of the legislation guaranteeing the right to early intervention services from birth. To assist school districts in serving young children with disabilities and their families, state legislation has mandated the formation of local interagency early intervention committees (IEICs) in which all school districts must be involved along with representatives from the departments of public health and social services, current service providers, county boards, parents, early childhood family education, and other public and private agencies. The intent is for agencies and parents to work cooperatively to identify services, establish programs, and/or provide services as needed for young children with handicaps and their families. There are now 98 IEICs in Minnesota.

Several mechanisms are currently in place to help implement the birth and IEIC mandates. Two of them are the Interagency Planning Project for Young Children with Handicaps and the Regional Early Childhood Coordinators project. Both of these federally funded projects are providing technical assistance and inservice training, including facilitating IEIC meetings, providing information to IEICs and others in the community, training on transition services, disseminating information on integration, conducting communications workshops, operating lending libraries, linking with neonatal intensive care units, holding assessment workshops, developing regional directories, and publishing a statewide newsletter. The Interagency Planning Project has two staff members, one housed in the state Department of Education and the other in the state Department of Public Health . The other project has resulted in an early childhood coordinator being housed in each region of Minnesota to provide information on screening, referral, assessment, intervention, and interagency services. Both projects are in their second year of implementation.

As we look to the future, the hope is that our state interagency system will continue to be functional and provide valuable assistance to young children with handicaps and their families. •

Dr. Sandra Fink is an Education Specialist with the Minnesota Department of Education, Unique Learner Needs Section. For further information on the birth mandate or state interagency system, call her at (612) 296-5007.

Iowa

Increasing Integration

by Deborah Hansen

Iowa's public schools have offered Early Childhood Special Education (ECSE) services for children from birth to age seven since 1974. Having a mandate to serve young children with disabilities for over 15 years has allowed area education agencies (AEAs) and local districts to develop a comprehensive, statewide network of ECSE services. The primary model for serving three to five year old children has been self-contained center-based classrooms. This has resulted in limited opportunities for integration of preschool children with special needs into settings with typical young children. Efforts are being made at the state, regional, and local levels to develop policies, procedures and new program models that will enable districts to offer ECSE services that include quality integrated programming. The Iowa Department of Education, Bureau of Special Education, currently offers technical assistance to agencies interested in developing or refining integration and mainstreaming projects. The Bureau is also in the process of revising rules and guidelines to provide a variety of LRE options in public school and community facilities.

One approach to integrated programming that is gaining popularity in Iowa is the LRE facilitator model. The role of the facilitator is to identify programs in the community that are interested in and able to serve children with special needs. Facilitators assist in arranging placements; coordinate communication among special education personnel, the community program staff and parents; provide ongoing training and support to providers; and monitor the IEP process. Placements may combine participation in Head Start, kindergarten, private preschool or day care sites, with center-based or home intervention special education services. Facilitators emphasize supporting regular educators and design instructional programs to ensure that deliberate strategies to facilitate social interaction are implemented.

Other creative approaches to integrated programming have involved the establishment of cooperative service arrangements. For example, the Ames Community School District and Iowa State University Child Development Department have collaborated to provide an ECSE program and an early childhood program in the same classroom. A regular early childhood teacher and an ECSE teacher team-teach eight children with disabilities and 10 children without handicaps. The teachers implement a unique curriculum and planning process that emphasizes the development of social competencies and teaming between the regular education teacher and special education teacher.

In August, the Des Moines Independent Community School District and the Iowa Department of Education will sponsor the replication of the LEAP program. LEAP, Learning Experiences...An Alternative Program for Preschoolers and

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Progress Reports

North Dakota

Advancing Statewide Services

by Alan Ekblad

In 1983, the North Dakota legislature mandated that public schools provide services to all children with handicaps, ages three to six, by July 1, 1985. This legislative act stimulated continued efforts to build a comprehensive system of intervention services for infants, toddlers and preschool children with handicaps and their families. Three major outcomes of this mandate were: 1) the transfer of responsibility to the public schools for the provision of services to children with handicaps ages three through six; 2) the provision that infant development programs be created to serve infants and toddlers from birth through two years of age; and 3) acknowledgement of the need for these two programs to work closely together. The two programs are currently administered under separate state departments, the Department of Public Instruction (preschool handicapped programs) and the Department of Human Services (infant development programs).

The service delivery model structure within both programs is primarily determined by a philosophy of meeting the needs of individual children and families. Generally, service delivery is home-based, center-based, or a combination of the two for preschool children, and home-based for infants and toddlers.

In 1985, the North Dakota Early Childhood Tracking System (NDECTS) was initiated. This system was designed as an interagency referral and monitoring system to locate and "follow" young children and infants who at high risk for the development of handicapping conditions or chronic illness. The system is currently being piloted regionally and on the four Indian reservations in the state, and will be implemented statewide by the fall of 1990. In March, 1989, the tracking system recieved the National Exemplary Program Award from the American Council on Rural Special Education.

In October, 1987, the Governor of North Dakota officially designated the Department of Human Services Developmental Division as the lead agency to oversee implementation of Part H of P.L. 99-457. The North Dakota Interagency Coordinating Committee (NDICC) was also established by the Governor at that time. The primary mission of the NDICC is the development and implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for families with handicapped infants and young children from birth through age five. As a part of this broad mission, five priority planning targets have been established: 1) family involvement, 2) program standards and guidelines, 3) child identification, 4) personnel development, and 5) interagency collaboration. Subcommittees have been assigned to address the above target areas. Through the work of the committee, North Dakota will continue its efforts to refine and update the provision of comprehensive early intervention services across the state. •

Alan Ekblad is Coordinator of Special Education with the North Dakota Department of Public Instruction.

South Dakota

Enhancing Cooperative Efforts

by Becky Dravland

In February 1989, the Governor of South Dakota commissioned the South Dakota Interagency Coordinating Council for Special Needs Infants and Toddlers (ICC). Since its inception, the ICC, working together with state and local agencies/committees, has established priorities leading toward the development of a comprehensive, multidisciplinary, interagency program of early intervention services for infants and toddlers with handicaps and members of their families.

During the past two years, Interagency Coordinating Councils within the state have worked on a number of priorities including development of interagency child find systems; multidisciplinary evaluations of infants and toddlers with handicaps, along with assessments of the needs of the child's family; regional directories of early intervention services, resources and experts; and the development and implementation of a local, regional and statewide family support system. Model programs have been initiated in a number of areas, including an Infant Identification and Tracking System currently being piloted in four communities. This system identifies and tracks infants and toddlers with handicaps and those at risk from birth through periodic well-baby checks that can occur in either private or public clinics.

In addition, four other sites within the state have been selected for model activities. The Brookings Interagency Council initiated data collection activities pertaining to time and activities involved in case management and the development of Individual Family Service Plans (IFSP) for families with infants and preschool children with handicaps. The Aberdeen School District has explored the dynamics of including a registered nurse as an integral part of the early intervention team. Remaining sites have worked on establishing Interagency Coordinating Councils and systems for case management.

In an attempt to increase the public's awareness of early intervention services, an interagency public awareness program has also been initiated in South Dakota. This has taken the form of public service announcements on five South Dakota television stations, which provide information on early intervention services, and the distribution of child growth and development charts to parents of newborns through all hospitals in the state.

The mission of the South Dakota Interagency Coordinating Council is to insure that children with special needs and their families receive appropriate services within integrated settings. We believe that this goal can only be met in a atmosphere of mutual respect between agencies and families such that services are viewed as a cooperative effort by all of those involved. In the past several years, we believe that we have made significant progress toward attaining this end. •

Becky Dravland is Program Specialist with the Section for Special Education, South Dakota Department of Education and Cultural Affairs.

The Key to Effective Early Intervention Services: Family Involvement

by Maria Anderson

I was 29 years old when Nicole was born. Although I had been married for ten years, I had delayed having a child because my husband was in school. During this time, I pursued my career in special education by working as a teacher with children who had special needs, including intellectual and speech/language disabilities. I anticipated my child's birth with joy and looked forward to becoming a parent and engaging in all of the "typical" parent activities.

Life doesn't always happen the way we imagine and plan. My parenting experiences are not, and in many ways may never be, very "typical." I became a single parent and Nicole has multiple handicaps due to cerebral palsy.

From the age of 10 months until she was five and one-half, Nicole and our family received early intervention services from several developmental achievement centers and human services programs. We began receiving in-home services, then moved to in-center services when Nicole was about two and a half. She began an early childhood special education program in the fall of her fifth year, which included some time in an integrated kindergarten class. This year she participates in an integrated kindergarten class with support services, and next year she will be in an integrated first grade classroom.

Nicole's development has continued to delight and sustain me. I have had to accept the reality that she will never walk, but watching her do independent floor sitting and maneuver her power wheelchair gives me as much pride. Her speech is still somewhat difficult to understand, but she has moved beyond using augmentative communication systems to speaking in six to ten word sentences. The skills she has attained are all the more valuable to me because they come as the result of our persistence, courage and ability to integrate her disability into our lives.

The progress Nicole, now age seven, has made in her development has been paralleled by my own gains. Because my parenting experiences are very different from those of my friends, I have found an important common ground in meeting with other parents whose children have disabilities. I continue to develop my own definition of what "success" means for her development and for my parenting, and I try not to compare either of us to other families.

Nicole's early intervention services, a network providing physical and occupational therapies, speech and language therapy, family support and training, equipment, respite and case management, were delivered in a segmented fashion without the coordinated team efforts now in place. Because Minnesota is now serving children from birth with interagency teams from education, human services, and health, it is my hope that other children and families will be served in a more comprehensive way.

As I talk with parents in my position as Early Childhood Coordinator at PACER Center, I continue to be impressed with how well most of them know their children. Although the early intervention process can seem complex and overwhelming, families must never doubt the importance of their involvement because they not only have a wealth of information to add, but also are the best resource in planning appropriate goals and services for their children. Involving siblings and extended family members in early intervention activities also facilitates learning and eases the primary caregiver's responsibilities.

The family unit provides an integrated environment, and early intervention services can and should support the child and family's integration into their community. Such services provided at an early stage have the potential to make integration the norm, rather than something only a few children enjoy.

Program planning means not only working on skills for the present, but using them to build toward the future. Parents and professionals need to begin during these early years to plan and create a "vision" for their child, a process that enables them to focus on long range goals. For example, while it is important to me to have Nicole learn as much as she can in the school curriculum, my vision for her life includes developing friendships and becoming as independent as possible in her community. As a result, the highlights of her integrated kindergarten experience last year were not only that she progressed in her development, but that she was invited to a classmate's home to color Easter eggs and asked to dance at a school dance.

The new early intervention service model offers an exciting challenge and vehicle for meeting needs of families and children. It is critical for families and professionals to develop partnerships that not only value each team member's contribution, but also allow for creativity and flexibility in planning and delivering services. Only then will we bring about the quality early intervention services that children and families deserve. •

Maria Anderson is the Early Childhood Coordinator at PACER Center, Inc., (Parent Advocacy Coalition for Educational Rights), Minneapolis, MN.

Family-Centered Intervention: Issues and Opportunities

by Jean Ann Summers

Ten years ago, professionals in the field of early intervention spoke of "parent involvement": that is, they were concerned with getting active participation from parents in their child's early intervention program. Over the years, however, we have come increasingly to recognize that children need more than intensive early stimulation to enhance their cognitive, motor, and language skills. We now know that one of the most important foundations for later success is a supportive home environment. Therefore, families are not merely adjuncts or even partners in providing services for the child, but should be a focus of early intervention. This realization has led us away from child-centered and program-centered perspectives, to a family-centered perspective of the responsibilities of early intervention. Rather than asking the parents to be "involved" (e.g. to support the program), we are asking how early intervention can support the family. This shift in perspective opens a new realm of opportunities and challenges.

One of the first challenges is defining exactly what differences -- what impacts or outcomes -- early intervention should be making for families. The guiding principle in early intervention is that children who receive services at this young age have a stronger foundation on which to build skills for successful life in the community. Applying that same principle to families, it seems logical that early intervention should be similarly concerned with providing families with a strong foundation of "marathon" skills needed to meet the lifelong challenges that come with having a child with a disability. The question is, just what are those skills? How can we help families acquire or strengthen them? These are fundamental questions that must be answered if we are to define the appropriate role of early intervention in family life.

> ***"We don't expect you to take away all the pain...We do expect that you not add MORE pain in the way you provide services."***

A second major set of opportunities and challenges centers around a corollary to family-centered services: if families are the central focus, then families should be in charge of the whole process. Family control means different things to different early intervention specialists. For some it means "empowerment"-- giving families the skills to solve their problems with minimal reliance on service systems. For others it means recognizing families as the real experts on their child and respecting family preferences with regard to all decisions about services. For still others, family control means providing families with a range of choices for everything, including the option to delegate some or all of their control to someone.

Perhaps all of these dimensions of family control are correct. Perhaps teaching families HOW to assert control is one of the marathon skills that ought to be the responsibility of early intervention. Beyond developing a consensus about its meaning, a bigger challenge lies with the fact that, however defined, family control is a "best practice" principle not often realized.

A final set of opportunities and challenges surrounds the notion that family-centered necessarily means "family-friendly" services. If families are truly to be supported and be in charge, then early intervention programs need to be attractive and comfortable for them to use. As one mother put it, "We don't expect you to take away all the pain that goes with having a child with special needs. We do expect that you not add MORE pain in the way you provide services." To most families, a family-friendly early interventionist is a professional who takes the time to get to know the family, and to develop a bond of friendship and empathy that is emotionally supportive. Family-friendly means being respectful of the family's privacy and integrity, and attending to differences while avoiding labels and stereotypes. Family-friendly assessment may not be assessment at all, in the way most professionals know that term, but a process of helping the family to express their strengths and needs through an informal exchange between professional and family. It means honest, complete and simple explanations about the child's needs and about services, phrased in terms the family can understand. It means being immediately responsive to immediate needs. In short, family-friendly early intervention implies an informal, emotionally supportive, fluid process that can be revised at a moment's notice during the rapidly changing period of infancy.

> ***"...as they say in the Nike commercial: Just do it."***

Family-friendly concepts provide us with opportunities to develop programs that are as satisfying to the people who work in them as they are to the families they serve. A challenge will be in learning how to teach early interventionists to be family-friendly. An even greater challenge will be in developing programs and services that are accountable without being stifling to the families they serve.

In short, embracing a family-centered concept in early intervention has opened a range of opportunities for services to infants and toddlers with disabilities and their families. We have the opportunity to expand the role of early intervention to provide lifelong skills to families. We have the opportunity to give families meaningful control over their lives, or, if you prefer, to avoid taking it away. And we have the opportunity to develop services that are refuges of warmth, humanity, and informality in the midst of this increasingly impersonal and bureaucratic society. The challenge is, as they say in the Nike commercial: Just do it.•

Dr. Jean Ann Summers is Director of the Kansas University Affiliated Program and a Program Coordinator at the Beach Center on Families and Disability, University of Kansas.

Early Intervention: One Family's Experiences

Chloette and Jerry Haley have an 18-month old son, Luke, who has William's Syndrome. The family formerly resided in the Twin Cities metropolitan area; they now live in a town outside the Twin Cities. In this interview, they share their experiences in seeking services for Luke from a variety of providers.

Tell me about the experience of learning about Luke's special needs.

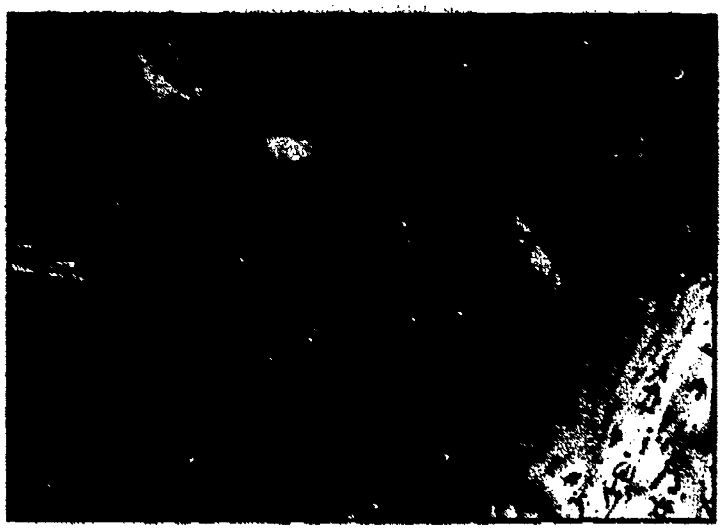
Luke was born with a heart murmer, which the doctor told us not to worry about, and had some problems with jaundice and low blood sugar. At about two weeks he started crying for around 16 hours a day. We kept asking the doctors what was going on and they told us we had a colicky baby.

The doctors started doing tests when Luke was four months old; they suspected William's Syndrome at that point, but didn't tell us. The pediatric cardiologist checked his heart again when he was six months old, and found he had a congenital heart defect. This doctor also told us that while he couldn't be sure, he thought Luke had William's Syndrome.

The specialists we contacted didn't give us a lot of information on William's Syndrome, so we went back to our regular pediatrician, who told us that children with this syndrome generally have IQ's between 80 and 100. I called the March of Dimes and they gave us more accurate information: children with the syndrome have IQ's between 40 and 70 (we think Luke will be on the high end of this range) and are typically mildly to moderately handicapped. The diagnosis had not been confirmed yet, but everything started to make sense after the call to the March of Dimes. We also contacted the William's Syndrome Association at this point and got further information.

What kind of early intervention services did Luke receive after the diagnosis was confirmed?

We got in touch with our school district and they told us about an early learning and development program, which got us in touch with a social worker; a public health nurse; and speech, physical, and occupational therapists. We also contacted a developmental pediatrician. There were, and continue to be, a number of people who come in and give us respite care.



What have been the greatest frustrations in getting services for Luke?

Our move has been really frustrating because the school districts all do everything differently. Here, they are basically using one person, an early childhood teacher, as Luke's main contact. This teacher consults with the occupational and physical therapists. Luke had more direct contact with the therapists in our previous county. I don't see how an early childhood teacher coming out once a week for 45 minutes to an hour is going to make a real difference in Luke.

Previously, the county paid for Luke to go to day care three mornings a week and they won't do that here. We're trying to get that for him again so that he gets the challenge from other kids and modeling opportunities to kind of enhance what he gets from the early childhood teacher. Not having that day care opportunity three mornings weekly has really made a difference for Luke. He is lonesome for other kids and he's much fussier than he used to be. I also don't see him making as much progress as he was.

Another thing about the day care relates to his long-term goal of going to regular kindergarten. It would be quite a shock to Luke to all of a sudden be six and stuck in a room with a bunch of kids. We believe that he needs to be integrated now so it can be a more gradual approach.

It's been our impression that there are quite a few holes in the (early intervention) system because it's so new. One weak link is having the school take over those services; it's really hard to figure out who's in charge. Is the county in charge? Our medical plan? The school district? That's why we got the developmental pediatrician: he's in charge. He monitors Luke's progress medically, developmentally, and physically. He coordinates everything and consults with all of the people involved with Luke.

The biggest trick of all, though, is figuring out what your kid needs. I still don't know how I'm supposed to do that. It's like you're supposed to be an expert on a disability that there is very little known about. I had to sit down with seven people one day to do Luke's education plan and be on top of it in terms of what was good and bad about the plan. How is a parent with their first child supposed to do that? Yes, I know my child better than anyone else, but I'm not a developmental specialist, or an occupational therapist, or an expert in speech development. It's

Haley, continued on page 18

IFSPs: Implications for Implementation

by Carla Peterson

Public Law 99-457, mandating early intervention services for young children with special needs beginning at birth, shares many features with P.L. 94-142, but contains two important changes for children under three years of age: it calls for services aimed at an entire family rather than focusing on the child, and requires that, when necessary, these services be provided by multiple agencies. Delivery of these early intervention services is guided by the Individual Family Service Plan (IFSP) developed by the family in consultation with an interdisciplinary team, much as the Individualized Education Plan (IEP) guides service delivery for current special education students.

The implementation of IFSPs holds many implications for children, families, and professionals in relation to service delivery in the 1990's and beyond. If we are to fulfill the spirit of P.L. 99-457, the deficit model theory underlying traditional special education must be changed. This model, which implies that families are not functioning adequately and are displaying deficits in need of remediation, has two serious limitations. It does not provide guidelines for resolving conflicts between the needs of individual family members, nor does it provide guidance in designing and selecting a means for meeting family needs. In place of the deficit approach, many researchers and practitioners have drawn upon the family systems perspective to recommend both theoretical and procedural guidelines for current and future practice. From this viewpoint, individuals, families, and society are parts of a system, and the "fit" between components is a critical concern. This perspective suggests that family-based interventions must be designed to support the child's development and strengthen the family. This perspective is not intended to be value-free, but calls for recognition of and respect for the values held by each part of the system in all interventions.

In line with this perspective, Carl Dunst and his associates at the Western Carolina Center have been leaders in calling for an "enabling and empowering" approach to working with families. This approach assumes that children and families have existing strengths, as well as the capacity to become more competent. Practice emphasizes an active role in early intervention for families, and the coordination of services in ways that empower them to become as self-sustaining as possible. Embracing this approach necessitates a rethinking of commonly used special education procedures when developing IFSPs. Service plans must be fluid rather than static; that is, frequent modification of goals, methods, and desired outcomes must be permitted in response to changing needs of the child and the family, priorities, situations, and sources of support.

Given that this approach could be widely adopted, some important issues remain to be resolved in the implementation of IFSPs. Most important are the naming of a case manager and the mandate for interagency coordination. P.L. 99-457 specifies that an individual most relevant to the needs of a child and family be designated as case manager and assume responsibilities for service coordination. However, this does not imply that the case manager, nor his or her employing agency, would necessarily be the only intervenor for a family. Rather, appropriate and desired services are to be provided in an efficient manner by any number of agencies working in concert. At this time, all states have identified a lead agency to initiate this collaborative system, and all states have an interagency coordinating council in place. The authority of these entities to secure the full cooperation of various agencies in service delivery is not specifically outlined and will most likely develop over time.

The full implementation of P.L. 99-457, and concomitant use of IFSPs, will be a challenge for the next decade and beyond. By monitoring its implementation and related state policies, as well as being active in quality control efforts, professionals can assure not only that the intent of the law is met, but that high quality services are delivered to families. •

Carla Peterson is a graduate student in the School Psychology program at the University of Minnesota.

Minnesota Regional Early Childhood Coordinators

Minnesota families who have a child under age six with a handicapping condition can contact the Regional Early Childhood Coordinator in their area for information on early childhood screening, referral, assessment, intervention and evaluation services. The following is a list of regions, the counties in each, and their coordinators:

Regions 1 & 2: Kittson, Roseau, Lake of the Woods, Marshall, Pennington, Red Lake, Polk, Norman, Mahnomen, Clearwater, Beltrami. **Vicky Grove, Thief River Falls, (218) 681-8005.**

Region 3: Koochiching, Itasca, Aitkin, St. Louis, Carlton, Lake, Cook. **Marilyn Lindaas, Duluth, (218) 723-4150.**

Region 4: Clay, Becker, Otter Tail, Wilkin, Grant, Douglas, Traverse, Stevens, Pope. **Lorrain Jenson, Fergus Falls, (218) 739-3273.**

Region 5: Wadena, Cass, Crow Wing, Todd, Morrison. **Sara Schoepf, Staples, (218) 894-1930.**

Regions 6& 8: Big Stone, Swift, Kandiyohi, Meeker, Lac Qui Parle, Chippewa, Renville, McLeod, Yellow Medicine, Lincoln, Lyon, Redwood, Pipestone, Murray, Cottonwood, Rock, Nobles, Jackson. **Pat Lytwyn, Marshall, (507) 537-1481.**

Region 7: Mille Lacs, Kanabec, Pine, Benton, Isanti, Chisago, Sherburne, Stearns, Wright. **Melody Peterson, St. Cloud, (612) 255-4862.**

Region 9: Sibley, Nicollet, LeSueur, Brown, Watonwan, Blue Earth, Waseca, Martin, Faribault. **Becky Byrn Petzel, North Mankato, (507) 389-1882.**

Region 10: Rice, Goodhue, Wabasha, Steele, Dodge, Olmsted, Winona, Freeborn, Mower, Fillmore, Houston. **Ann Kirchhoff, Rochester, (507) 288-1282.**

Region 11: Anoka, Hennepin, Ramsey, Washington, Carver, Scott, Dakota. **Sue Benolken, Arden Hills, (612) 490-0058.** •

Project Empowers Families

Families Involved in School and Community (FISC) is a project that's seeking to build a strong framework for provision of community-based support services to individual families that have a preschool- or elementary-aged child with a severe disability. The three-year federally-funded project, conducted by the University of Minnesota's Institute on Community Integration and St. Cloud Community Schools in St. Cloud, Minnesota, operates on the premise that an individualized family systems approach should be used to enable and empower families as they take an active role in finding community and educational resources to meet their needs.

The project consists of three stages. The first involves project planning, development of family assessment strategies and the identification of community resources in the St. Cloud area. During this stage, the common strengths and needs of families that have a child with a disability have been identified through an interview-based survey with the families involved in the project. The information gathered from this process will next be used to develop a more detailed assessment.

Stage two will include in-depth, individualized family assessments and the development of an IFSP for each. Project staff will assist families in locating and using formal and informal support systems in the community to meet their needs.

The final stage of the FISC project will encompass IFSP implementation, program evaluation, and dissemination of information.

The project is currently at the end of the first stage. The expected completion date is 1991. •

Contributed by Kevin McGrew, School Psychologist and the Project Evaluator, and Susan Johnson, Project Assistant.

FACT FIND: An Innovative Service

The Center for Early Education and Development at the University of Minnesota is conducting a pilot project called FACT FIND to develop a model that will create communication links between the University of Minnesota and the state policy makers and policy influencers. The goal is to assist legislators, their committee staff, state agency personnel, and the Governor's office to become well-informed about issues that underlie the creation of programs, regulations and policies that affect children and families. This policy-making community is bombarded with information from a variety of sources (i.e., lobbyists and advocacy groups), the credibility of which can sometimes be challenged. The biased nature of some of the data can result in poorly conceptualized legislation. Decision makers also indicate that sometimes the research that could be the most helpful to them is in a form that is not particularly useful or accessible. FACT FIND is based on a belief that the research community at the University, representing diverse disciplines, can be a valuable nonpartisan resource to policy makers. A University, by its very nature, offers the range of expertise needed for making well-informed policy decisions.

FACT FIND "demystifies" research, making it accessible to legislators and bridging the gap between "the trenches" and "the ivory tower." This is done by providing information in non-technical summary form, such as fact sheets and audio tapes. The information consists of such items as objective assessments of current issues, summaries of research, and examples of programs and demonstration models. In addition to the unsolicited distribution of materials, the model includes the FACT FINDER, a person who takes the time to get acquainted with legislators, government staff, and child advocates. This personal contact creates opportunities to provide individualized responses to questions. •

Contributed by Erna Fishhaut, Program Coordinator, Center for Early Education and Development at the University of Minnesota.

Study Follows Parents of Premature Infants

The advent of home monitors that sound an alarm when a premature infant stops breathing or their heart rate slows has been the subject of controversy since the early 1970s. There has not been documented consensus on the effects that monitors have on either the medical management of infants at risk for apparent life-threatening events or the mental health of parents. Now, researchers at the University of Minnesota and Minneapolis Children's Medical Center have further studied the effects of monitoring on psychological well-being of parents, and the results suggest not only that monitoring can have a positive impact, but that professional educational and support programs are an essential part of maintaining the psychological health of parents with premature infants.

Barbara Leonard and Sheryl Scott of Maternal and Child Health in the University's School of Public Health, and Jane Sootsman of the Minneapolis Children's Medical Center, have collaborated on a study of the psychological effects of home monitors on first-time parents with premature infants. Parents of infants born between 26-34 weeks gestation were compared with parents of full-term normal weight infants; all were first-time parents. The parents of premature infants were divided into two groups. The first had children on home monitors and was enrolled in the Infant Apnea Evaluation Program, a hospital sponsored parent support group. The program provided structured three-hour educational sessions prior to the infant's discharge. While the infant was on the monitor at home, family support through this program included phone calls once every one to two weeks to check on the status of the child, monthly parent support groups, educational sessions for child care providers and relatives, and a 24-hour telephone information line. The second group of parents with premature infants received routine professional services in the hospital and the child was discharged to a pediatrician in the community. Based on medical criteria, home monitoring was not

Infants, continued on next page

Infants, continued from page 12

recommended for these infants, and the hospital did not provide these parents with formal support or follow-up after discharge. The third group, parents of full-term infants, was obtained from a separate family practice clinic.

The study found that the parents of nonmonitored premature infants reported consistently higher psychological symptoms that the other groups of parents, especially evident in terms of depression, sensitivity, hostility, paranoid ideation, and a global index of psychological health. In fact, they found that two to three times more parents of premature nonmonitored infants reported symptoms that suggest a need for intervention. Fathers of these infants particularly contributed to this level of distress. Conversely, the parents of the monitored infants did not report increased depression, anxiety or other psychological symptoms; they reported no more stress than first-time parents of full-term infants.

While the study reveals that the monitor itself provided some reassurance to the parents, the research also strongly suggests that a structured professional support system is essential in promoting parental well-being, especially for parents of infants with critical health needs such as those of premature infants. •

Contributed by Barbara Leonard, Ph.D., Maternal and Child Health, School of Public Health, University of Minnesota.

Early Intervention Education Offered

The Minnesota Interdisciplinary Program in Early Intervention, at the University of Minnesota, prepares students from a variety of human service disciplines to work with children, and families of children, birth to age three who may be at risk or have developmental delays. The program, which began in 1988, integrates content and shares faculty from special education, school psychology, speech/language pathology, social work, public health, nursing, physical therapy, and occupational therapy. Students are admitted to the program from each of these academic areas. FFI call Jan Jernell, Program Coordinator, at (612) 624-5547. •

Program Promotes Social Interaction Skills

Preschool children with handicaps are at significant risk for problems in the development of social interaction skills. As a result of early learning problems and initial skill deficits, as well as frequent educational placement in segregated or atypical settings, many young children with handicaps experience social skill deficits that, without treatment, can be expected to worsen and intensify throughout life. The consequences of this developmental course represent a significant cost to children, their families, our schools, and society at large. Yet in spite of the fact that recent research has identified a number of ways to prevent or remediate many of these problems, few efficient and effective intervention procedures are available for use in the community preschool programs that typically serve these children. It has become increasingly obvious that systematic efforts are needed to reduce the gap between research knowledge and practical application for promoting social skill development in early childhood special education.

The U.S. Department of Education's Office of Special Education and Rehabilitation Services has funded a project directed by Dr. Scott McConnell of the University of Minnesota's Department of Educational Psychology (along with Samuel Odom of Vanderbilt University) to conduct a four-year research program to identify and develop early childhood special education program features that enhance the social interaction skill development of young children with handicaps. The purpose of this project is to carefully study the effectiveness and efficiency of various social interaction skill intervention procedures, and to collect information that will help early childhood special education professionals make informed decisions about the adoption of these procedures in their programs. Specific project goals are:

- To describe existing practices for promoting development of social interaction skills among preschool children with handicaps, including teachers' preferences for types and amount of intervention provided in their classroom and obstacles that may interfere with implementation of known interventions;
- To develop replicable, usable intervention packages for three different sets of program features (i.e., environmental arrangements, child-specific interventions, and peer group interventions), translating recent research findings into state-of-the-art practices for use in existing preschool programs;
- To compare the relative benefits and costs of implementing different combinations of these program features in existing community preschool programs; and
- To evaluate the effects of different combinations of program features and characteristics of a child's next educational environment on the generalization and maintenance of social interaction skills.

Major activities to meet these goals include: (a) a large-scale descriptive study of intervention procedures and social development outcomes for children in 20 classrooms (10 in Minnesota) completed during 1987-88; (b) experimental development and validation of three intervention components that can be used in typical preschool settings, completed during 1988-89; (c) a comparative study of the relative effects of implementing one, two, and three of these components across 24 classrooms (12 in Minnesota), planned for 1989-90; and (d) followup of participants in the comparative study and replication of the most effective and efficient combination of program features in 10 classrooms (five in Minnesota) during 1990-91.

It is hoped that the results of this project will contribute to the growing knowledge base on the development of social interaction skills among preschool children with handicaps. More important, however, is the project's development of intervention procedures that teachers will be able to implement in their classrooms, and that can be expected to produce important and long-lasting changes in the social interaction skills of many early childhood special education students. •

Contributed by Scott McConnell, Associate Professor of Educational Psychology, University of Minnesota. For further information contact him at N548 Elliott Hall, University of Minnesota, Minneapolis MN 55455.

Early Intervention and Least Restrictive Environment

by Samuel L. Odom and Mary A. McEvoy

A provision of the current federal legislation governing educational services for preschool-aged and older children with disabilities is that they should receive an appropriate educational program provided, when possible, in the least restrictive environment (LRE). For most children, LRE is considered as programming provided with or in close proximity to other children without disabilities. Since public schools are the agency most often responsible for early intervention for three to five year old children with disabilities, and they typically do not offer classes for children that age who are normally developing, creative alternatives for providing a LRE must be sought. These alternatives might include placing young children with disabilities in (a) programs designed for and containing primarily same-aged children without disabilities (i.e., mainstreamed programs); (b) a nonintegrated early intervention program for part of a day and a mainstreamed day care center for the remainder of the day; (c) a special education program into which normally developing children are integrated (i.e., an integrated special education program; or (d) a nonintegrated early intervention program housed in a regular elementary school with opportunities for integration with slightly older kindergarten children. Of these alternatives, we feel that the mainstreaming option comes closest to the spirit of LRE implied by the law. However, decisions about placement must ultimately be based on the educational needs of the child.

> ***"...we feel that the mainstreaming option comes closest to the spirit of LRE implied by the law."***

The research literature tells us a few things about what happens when integration occurs. The most frequently documented finding has been that when preschool children with and without disabilities are placed in integrated play groups, a form of social segregation occurs. That is, the normally developing children often choose to play with their normally developing peers, to the exclusion of the peers with disabilities. This pattern of social separation appears to be most pronounced for children with moderate and severe developmental delays, although recent analyses of verbal exchanges and friendship patterns for children with mild developmental delays reveal similar forms of preferences by the normally developing peers.

Despite this segregation that naturally arises in some integrated play groups, there is evidence that the integrated environment offers opportunities for learning social and play skills that do not exist in nonintegrated settings. Moreover, when opportunities for social integration are specifically planned for and provided through large group activities designed to foster affectionate and prosocial behavior, or through structured social integration activities, greater levels of social integration appear to occur. These increased levels of social integration appear to have positive effects on the social competence and language skills of young children with disabilities.

The impact of LRE on other aspects of development for young children with disabilities is less clear. It appears that children with disabilities and normally developing children may benefit developmentally from placement in integrated classes as much as they do when placed in nonintegrated classes. Most of these studies have been conducted primarily in integrated special education classes located in model integration programs. The single comprehensive study conducted in mainstreamed classes produced equivocal effects. In all likelihood, the quality of the instructional environment and the curriculum employed will have a greater impact than the integration factor for developmental skills other than social and language skills. However, there are issues other than skill development (e.g., the legal mandate, the normalization principle, parent preferences, etc.) that make LRE settings the placement of choice for many young children with disabilities.

> ***"For us, the most pressing question is whether individualized educational programs designed for children with disabilities may be provided as effectively in LRE, and specifically mainstreamed environments, as in specialized early intervention programs."***

Many questions and issues related to LRE remain unanswered. For us, the most pressing question is whether individualized educational programs designed for children with disabilities may be provided as effectively in LRE, and specifically mainstreamed environments, as in specialized early intervention programs. A similar issue is how related services (e.g., speech, occupational, physical therapy) might be efficiently provided in settings away from the public schools. Finally, bridging the gap between the differing educational and instructional philosophies existing within special education and early childhood education will be a major challenge for LRE implementors in the future. •

Dr. Samuel L. Odom is Associate Professor of Special Education at George Peabody College of Vanderbilt University. Dr. Mary A. McEvoy is Research Assistant Professor of Special Education at that institution.

Social Integration in Action!

Tuesdays and Thursdays are busy days at the Sunrise Education Center in White Bear Lake, a suburb of St. Paul, Minnesota. On those two days, students, parents, and teachers from the District's Early Childhood Special Education and Early Childhood Family Education programs come together for two and a half hours of learning, playing, and fun.

For the past three school years, teachers and administrators in White Bear Lake have been working together to actively promote increased integration between students and families in Early Childhood Special Education (ECSE) and Early Childhood Family Education (ECFE) programs. Separately, each of these programs is fairly typical for school districts in their region. What sets White Bear Lake apart, however, is its blending of the two programs into a creative approach to social integration.

The school district operates six half-day classrooms for preschool children with handicaps, with three classes meeting each morning and three more each afternoon. Each classroom is cross-categorical, serving children from three to five years of age with developmental interventions that focus on each child's strengths. Typically, one teacher and one educational assistant are assigned to each class of eight children. Professionals providing related services are either located on site, or visit the Early Childhood Center on an itinerant basis.

> ***"...the staff at White Bear Lake have one piece of advice for others interested in creating integrated early childhood programs: Try it!"***

The ECFE program also operates like many others. Approximately 600 children are served each week at the Sunrise Center; children from birth to two years of age come to the center with their parents one half-day each week, while children from three to five years old visit with their parents one or two half-days each week. All children are assigned to one classroom, and a range of activities are offered for children and parents, both separately and together.

During the 1985-86 school year, ECSE teachers asked to move their center-based program to the Sunrise Center, where students and families could have easier access to Family Education services. Key administrators, including the directors of Special Education and Family Education for the district, quickly lent their support. In the following year, integration of the two programs began. At first, teachers in ECFE and ECSE limited their efforts to a small group of students, who were integrated for small portions of a day. Steadily, however, staff members learned how to make their program work, and more and more integration took place.

During 1987-88, all students in ECSE were integrated into ECFE classes, with more deliberate efforts by staff to promote interaction between children. Based on the success of this effort, in this past school year ECSE and ECFE teachers began to plan and conduct classes together. Classroom programs have been fully integrated two days each week. On these days, ECSE and ECFE teachers have worked together to provide joint programming for their students.

Margie McMahon, the ECSE Coordinator in White Bear Lake, says that the model itself promotes integration among the students. She sees particular strength in the fact that activity groups are developmentally mixed, and that all developmental activities are jointly planned by ECSE and ECFE teachers to further promote attention to all children's needs. She also noted that both ECSE and ECFE teachers interact with all children in the combined programs; even specialized activities (for instance, therapies) are provided in the mainstreamed setting. One result of this close collaboration has been a certain amount of role release, with teachers from each of the disciplines gaining skills and approaches from their new colleagues.

White Bear Lake's integration effort has not been without minor problems. At the beginning, children seemed somewhat hesitant about joint activities, but this hesitation seemed to quickly dissipate through contact with their new classmates. Sometimes, class sizes during integration activities are too big; teachers respond by organizing several smaller group activities to more carefully structure students' experiences. Also, promoting continued involvement among parents of special education students is sometimes difficult due to work or family constraints. Finally, it took all staff members some time to get used to teaming, or planning and conducting classroom activities with another teacher. However, this has been an area of continued activity and appears to be an area of special strength.

Ms. McMahon has also noted some difficulty due to differences in funding and basic missions of the two early childhood programs. ECFE was designed and is operated for families--parents and children together. While children receive some "classroom" time when their parents are attending classes or discussion groups, much of the ECFE day is designed for parents and children together. ECSE, however, is more child-centered in its focus, and must be provided whether or not a parent can attend. Further, some state and federal funding requirements place restrictions on staffing patterns possible in both programs.

In the final analysis, however, the staff at White Bear Lake have one piece of advice for others interested in creating integrated early childhood programs: Try it! By getting teachers and parents together, and by talking about models that will fit their own situation, a program may develop that is as exciting and innovative as the one at White Bear Lake! •

This article was based on an interview with Margie McMahon, Early Childhood Special Education Coordinator for the White Bear Lake Area Schools. It was prepared by Dr. Scott McConnell, University of Minnesota. For more information on the integration of ECSE and ECFE programs, contact Margie McMahon at (612) 429-0271.

Mastery Behaviors: Motivation for Young Children with Developmental Delays

by Susan Hupp

What joy to watch young children learning through play. Rolling balls. . . shaking rattles. . . pushing buttons. . . pulling levers. All means of obtaining feedback about how their environment works. All means of learning. The concept of mastery motivation is concerned with just this type of learning through goal-directed exploration.

Mastery motivation is based on the notion that toys (or fun household objects) have functions. With persistent exploration, the function of the toys may be revealed. They may make noise, or move, or display hidden parts. As such, mastery behaviors are different from success. A child's use of mastery behaviors often results in success, but not always. If a rattle is not shaken hard enough, it may not make noise. If a lever is not pushed far enough, a door may not pop up. But, with persistent practice, a child usually will experience success and the pride that accompanies having figured it out.

Several years ago we became interested in studying the use of mastery behaviors by young children with developmental delays. We were concerned by reports of practitioners and researchers alike that older children with severe disabilities often are passive and that, when they encounter new environments, they wait for others to show them how to act and what to do. It seems that some children lack self-reliance and do not know how to use exploration to learn about new objects and new settings. Thus, we began a research project to understand how young children with severe delays use mastery behaviors to guide their learning.

Our study of young children with moderate and severe delays had heartening results. While it was true that some of them tended to be more passive, many of them explored with vigor, using strategies similar to those used by nondelayed children of the same developmental level. Some of the children, however, demonstrated very low levels of mastery behaviors. They weren't interested in exploring to discover the function of toys. As such, they did not experience a high level of success when playing

What can we do to support the use of mastery behaviors by young children with delays? Three steps may be helpful to parents and teachers. The first is to detect the use of mastery behaviors by children. The second is to select toys that have a high probability of eliciting the use of mastery behaviors. And the third is to arrange the physical and social environment to support a child's initiatives.

Detection. Mastery behaviors relate to the function of toys or objects. Therefore, it is important to distinguish between exploration that is related to function and exploration that is more general in nature. For example, children may hit or shove almost any type of toy. While they will get some feedback, such as the toy is heavy or hard, they don't get a high degree of differentiated feedback from these actions. And they don't learn how the toys work. By first determining the function of toys, the parent or teacher can identify the specific types of exploration that will lead the child toward success. Consider the Shape Sorter by Fisher Price. The functions of this toy are to (a) place a block in the correct puzzle form on top, (b) place a block through the correct hole, or (c) remove the block from the toy by opening a small door. Mastery behaviors include (a) relating the shapes to the box, such as by putting the shapes near the holes or puzzle forms or attempting to put the shapes in the top holes or the front doors, or (b) manipulating the doors in an attempt to open or close them. General exploration that would not be considered evidence of mastery behavior includes banging or shaking the box, sliding the box, passively holding the shapes, turning the box over, or pushing the box or shapes away.

Toy selection. Two factors appear to be important in toy selection. Researchers have found that the level of difficulty of the toy affects a child's understanding of ways of manipulating the toy and the child's interest in the toy. Children may not use mastery behaviors with toys that are too difficult because they simply do not comprehend their function. Conversely, toys that are too easy may not peak a child's curiosity. Secondly, toys that are consistently responsive to a child's manipulations may result in a greater use of mastery behaviors. Toys that don't react in a predictable manner, perhaps because they are broken or are physically too hard to manipulate, may promote less exploration and less practice of successful manipulations.

Environmental arrangement. Both the social and physical environment may affect mastery behavior. Social referencing is a powerful tool that a child may use to gain assurance about a situation. Specifically, with social referencing a child will turn and look at an adult to "read" the adult's reaction about the situation. During play with toys, a child may want to elicit an adult's reaction to determine if the child should continue to try. Adults can provide positive (smiles), negative (frowns), or neutral reactions to children. Researchers have found that positive reactions are associated with increased play by children.

Accessibility of toys, within a child's reach or visual regard, is an important aspect of planning the physical environment. Accessibility has been shown to increase both the amount of play and requests to initiate play.

In summary, mastery behaviors serve an important function for children in that they teach a child how the environment works and the properties of specific toys and objects. While the use of mastery behaviors by children with cognitive delays often is equivalent to nondelayed children who function at the same level, some children need an extra-supportive environment to encourage their use of mastery behaviors. Strategies to facilitate the use of mastery behaviors include selecting toys of interest to a child, supporting the child with positive reactions to the child's social initiations, and arranging the environment to make toys accessible. •

Dr. Susan Hupp is Associate Professor or Educational Psychology and Associate Director of the Institute for Disabilities Studies at the University of Minnesota.

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Parents, is a project that incorporates training of the normally-developing child to intervene on the social skills, language skills, and classroom behaviors of their peers with handicaps. Two ECSE teachers will team teach eight children with disabilities and eight children without handicaps, and provide the parent involvement component of the LEAP approach.

Through active planning and cooperation at the state, AEA, LEA and university levels, Iowa Early Childhood Special Education services are making positive strides to provide more opportunities for young children with special needs to participate in early learning opportunities with their peers without handicaps. This endeavor will continue to require creativity, flexibility and the careful plotting of the components that are essential for quality programming for young children with special needs. •

Deborah Hansen is Coordinator of Early Childhood Special Education, Bureau of Special Education, State of Iowa.

> ***"A parent of a young child with a handicap is like a maestro trying to conduct an orchestra of musicians whom he/she has never met and who have never before played together. Despite the immense challenges presented, if the musicians get to know their conductor and each other, a synergism develops and together they can produce a piece of music far more beautiful than any one individual alone."***
>
> ***-- unknown***

Upcoming Events

August 11-13. Integration: Full Speed Ahead. Brooklyn Center, Minnesota. Sponsored by the Association for Retarded Citizens Minnesota. FFI call (612) 827-5641 or toll free 1-800-582-5256.

August 23-25. Upper Midwest Institute in School Psychology: Assessment and Intervention with Infants, Toddlers and Their Families. University Radisson Hotel, Minneapolis. Sponsored by Professional Development and Conference Services, University of Minnesota. FFI contact Lisa Brienzo, (612) 625-6616.

September 14-15. Creative Options for People with the Most Severe Disabilities. Minneapolis Hilton Inn. Sponsored by Options, Inc. FFI contact Jeanne Snyder at (507) 373-6064.

October 5-6. Integration Through Collaboration Retreat. Clear Lake, Minnesota. Sponsored by JOVE Associates and endorsed by ARC Suburban. FFI call (612) 253-0658 or (612) 743-3165.

October 11-12. Return of the Children: Prevention and Early Intervention in Developmental Disabilities. Radisson Hotel, Minnetonka, Minnesota. Sponsored by the Institute for Disabilities Studies, University of Minnesota. FFI contact Mari Forbush, (612) 627-4507.

October 19-20. Integrated Education: Realizing the Vision. Scanticon-Minneapolis Conference Center. Sponsored by the Institute on Community Integration at the University of Minnesota, the Minnesota Department of Education, and the Minnesota Association for Persons with Severe Handicaps. FFI contact Denise Callies at (612) 625-3061.

October 20-22. Harmony Through Communication: Working Together for Children. Duluth. Sponsored by the Minnesota Association for the Education of Young Children. FFI contact Cindy Belts at (612) 646-8689.

October 21-25. International Early Childhood Conference on Children with Special Needs. Marriott-City Center, Minneapolis. Sponsored by the Council for Exceptional Children's Division for Early Childhood. FFI contact the Early Childhood Intervention Program, Western Psychiatric Institute and Clinic, (412) 624-2012.

November 2-5. 1989 National Annual Conference of the National Association for the Education of Young Children (NAEYC). Atlanta, Georgia. FFI call toll free 1-800-424-2460.

December 1-3. Promises to Keep: Directing Research, Resources and Skilled Personnel to Support Infants, Toddlers and Their Families. Washington, D. C. Sponsored by the National Center for Clinical Infant Programs. FFI call Pat Guwang, (202) 347-0308.

Workshops on hearing impairments, vision impairments, and deaf/blindness in school-age children and young adults will be offered for Minnesota educators, parents and service providers beginning in October. Sponsored by the Minnesota Deaf/Blind Project. FFI contact Kathy Steffens, (612) 627-4616.

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that the findings provided general support for early education as a valid enterprise for young children with Down syndrome.

When children in the experimental group of the EDGE project became 11-14 years of age, follow-up data were collected, revealing that they were defying the stereotypes; that is, the vast majority of them were reading -- with comprehension -- at around a second grade level. In other words, most of them were educable and were well on their way to becoming functionally literate. Furthermore, their social adjustment was very good and their physical abilities reflected sports, recreation, and leisure interests that shattered the stereotype of "juvenile-like" interests and "rag-doll" muscle tone. Many were in integrated community recreation activites, several had competed successfully in highly demanding events during Special Olympics competitions, and several had become avid readers.

Progress Since EDGE

Looking back, though the home-based EDGE study was considered a pioneering effort in 1968 (institutionalization was still a common practice in the 1960s for infants with Down syndrome), today we realize that there was no need to operate the preschool as a self-contained program. Indeed, young children with Down syndrome are being integrated with regularity today. Moreover, there is a growing body of evidence to support their integration. For example, in one 1987 study researchers conducted a home-based infant stimulation program for eight children with Down syndrome. Obtaining good developmental outcomes (social, intellectual, motor, etc.) at the end of the program, the investigators arranged for the children to be mainstreamed (with support from itinerant specialists) in regular public school classrooms with same-age peers who did not have disabilities. Results showed that the skills of the children with Down syndrome continued to develop; particularly gratifying were their their attainments in reading.

The family-based orientation of the EDGE program, also innovative at the time, is the focus of choice for the majority of contemporary infant stimulation programs. In fact, it seems highly likely that the rationale for early education will continue to rest on the premise that the child with a disability cannot prosper unless his or her parent(s) prosper.

As the EDGE children have matured, we have continued to pursue ways to promote the development of people with Down syndrome of all ages and their families. Two recurring themes in our work have been the fighting of low expectations and providing parent and family support.

Fighting low expectations has taken place on several fronts. For example, recently we published an article showing that children with Down syndrome who had been through experimental early education programs were frequently prospering in educable classrooms and were showing good academic progress. We have also taken this message to parent-professional organizations such as the National Down Syndrome Congress.

Second, part of the project's support to new parents of children with Down syndrome was a guidebook we published in 1974 titled, "To Give An EDGE". In 1990, a completely revised edition of the book will be developed. It will contain descriptions of project participants as babies juxtaposed with descriptions of the same individuals as young adults. Moreover, we will be able to publish longitudinal data and photos that will show how each individual has progressed in motor, language and social development, as well as intelligence, over a 20 year period.

Lastly, perhaps one of the best measures of the effectiveness of early intervention efforts can be found in the story (*see page 3*) of a family involved in Project EDGE twenty years ago. David and Charlotte Colwell, and their daughter Holly, who has Down syndrome, reveal how the horizons of people with Down syndrome have been "stretched" since the Edge program was begun in 1968. This past spring, Holly graduated from high school; in the fall, she will begin vocational training at an area technical institute. •

Dr. John Rynders is Professor in the Department of Educational Psychology at the University of Minnesota.

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really frustrating.

What things have you learned about navigating the service delivery system with Luke?

We've learned that we have to do what's right for Luke and what we as parents can handle. I've learned to just be really up front with service providers and say, "No, I can't do that. That sounds too stressful. You're going to have to help me figure out how to do that if it's something Luke really needs." Taking care of Luke is a very exhausting job and we have to remember that we have to do things in the way that's best for Luke and for us as a family.

I've also learned what kinds of questions to ask to help get at people's attitudes about kids with special needs. That's been really important in looking for a day care provider for him here.

I think every parent should have a developmental pediatrician. It's like getting a second opinion for the early intervention services.

It's also essential not to feel shy about asking for help, both emotionally and financially. There are a lot of programs out there which families can and should take advantage of. For example, respite care is the greatest thing that ever happened to us; it lets us get away from the problem, the traffic, and the paperwork. We are also involved in a support group with other parents and this has been a terrific source of support for us. I would also recommend getting hooked up with advocacy organizations and getting informed about the laws. These organizations are sources of practical information for parents and can advocate for you when you need it most. •

The Haley's were interviewed by Susan Johnson, Graduate Research Assistant in the Institute on Community Integration, University of Minnesota.

Resources on Early Intervention

Journals

- **Early Education and Development.** This journal, published by Psychological Press Inc., is a new and innovative journal in the field of early intervention.

- **Journal of Early Intervention.** Published by the Council for Exceptional Children's Division of Early Childhood, this is a multidisciplinary journal aimed at professionals working in special education and related fields.

- **Research in Developmental Disabilities.** This journal offers a wide variety of research-based literature on developmental disabilities. Published by Pergamon Press.

- **Topics in Early Childhood Special Education.** A topical journal, published by PRO-ED: each issue focuses on one theme in early childhood special education.

Books

- **Bailey, D.B. and Wolery, M. (1989). Assessing Infants and Preschoolers with Handicaps.** Columbus, Ohio: Charles E. Merrill. This book addresses issues, considerations and procedures in assessing infants with handicaps. It is based on the recognition that the assessment of very young children is a process that requires different skills, uses different procedures, and takes different issues into consideration than the process of assessment for school-age children.

- **Cunningham, C. (1988). Down's syndrome: An introduction for parents.** Cambridge, Maryland: Brookline Books.
- **Stray-Gunderson, K. (1986). Babies with Down syndrome: A new parents' guide.** Kensington, Maryland: Woodbine House. These two books provide in-depth information on Down syndrome for parents and practitioners.

- **Dunst, C.J., Trivette, C.M., & Deal, A.G. (1988). Enabling and empowering families: Principles and guidelines for practice.** Cambridge, Maryland: Brookline Books. Written specifically for early intervention practitioners who are being asked to work with families, but who have not had extensive training in family systems assessment and intervention. The principles and operatives set forth in the book represent a framework and set of guidelines for promoting a family's ability to identify its needs and mobilize resources in a way that strengthens family functioning.

- **Odom, S.L., & Karnes, M.B. (Eds.). Early intervention for infants and children with handicaps: An empirical base.** Baltimore: Paul H. Brookes. This publication provides an in-depth examination into four topical areas: issues related to conducting research with infants and young children with handicaps; research on instruction or intervention practices within developmental skill domains; issues related to families; and a miscellaneous group including chapters on ecobehavioral assessment of classroom instruction, teacher education, and rationales frequently used in promotion of integrated programs as an option for some children.

New publication in development (tentative title and authors):

- **Rynders, J. E., & Horrobin, J. M. Giving an EDGE to people with Down syndrome: The growing up years (A guide for parents and professionals).** The expected publication date for this new book from Project EDGE is late 1990 or early 1991. It will contain descriptions of project participants as babies 20 years ago juxtaposed with descriptions of the same individuals today as young adults, including longitudinal data following progress in motor, language and social development as well as intelligence. Inquiries about this new book can be addressed to John Rynders, Ph.D., 255 Burton Hall, University of Minnesota, 178 Pillsbury Drive SE, Minneapolis, MN 55455.

Other

- **National Information Clearinghouse for infants with disabilities and life-threatening conditions.** An information and referral system providing current information about community services and resources that meet the needs of infants with disabilities and life-threatening conditions across the United States. Call toll free: 1-800-922-9234 or 1-800-922-1107 (S. Carolina).

In this issue . . .

- ***Building effective early intervention programs for the 1990s.***
- ***The story of EDGE, the early intervention pioneer.***
- ***EDGE graduate Holly Colwell, 20 years later.***
- ***Developing "family-friendly" early intervention services.***
- ***Early intervention progress reports from four Midwestern states.***
- ***Strategies to promote social and cognitive development.***
- ***Early intervention experiences of two Minnesota families.***
- ***Summary of early intervention legislation.***
- ***Implementing IFSPs.***
- ***Resources and coming events.***

IMPACT

Feature Issue on Early Intervention
Summer 1989

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The mission of the Institute is to apply its resources to improve the quality and community orientation of professional services and social supports available to individuals with developmental disabilities and their families. Institute efforts are directed at facilitating the independence and social integration of citizens with developmental disabilities into the mainstream of community life. Inquiries about the Institute or IMPACT can be directed to:

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