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ABSTRACT

This handbook provides guidelines for implementing an early intervention model, the Parent Infant Nurturing Group (PING), for infants with or at risk for developmental disabilities born to high-risk parents (special needs or with mental retardation). The handbook is a product of Project CAPABLE (Communities Assisting Parents To Be ABLE), a statewide project in Ohio which has provided inservice training, ongoing technical assistance, and replication services to over 800 service providers. The handbook is organized into five chapters. Chapter 1 focuses on the underlying intervention philosophy, the basic goals and objectives of early intervention with families where parents have special needs/mental retardation, and a description of the PING program. Chapter 2 presents a checklist for initial identification and further information about parents with special needs/mental retardation. Chapter 3 presents strategies and approaches to starting and successfully maintaining an early intervention program for this population. Chapter 4 describes an evaluation approach which examines changes effected by the program and the Individualized Family Service Plan in families in which parents have special needs/mental retardation. Chapter 5 offers an annotated listing of audiovisual materials, manuals, curricula, programs, and a bibliography organized into relevant material for each of the four chapters. (Contains 74 references.) (DB)

# PARENTS WITH SPECIAL NEEDS/ MENTAL RETARDATION

## A Handbook for Early Intervention

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This handbook is dedicated to the families who inspired the development of this approach, to the PING staff at UACCDD who serve them, and to the members of the CAPABLE resource teams throughout the State of Ohio.

# INTRODUCTION

In 1983, the University Affiliated Cincinnati Center for Developmental Disorders (UACCDD) received funding through a three year grant, a Maternal and Child Health Special Project of Regional and National Significance (SPRANS), to develop a model early intervention program for infants with or at risk for developmental disabilities born to high-risk parents unable to utilize existing early intervention resources for reasons related both to the family and to the service delivery system. The model grew out of our realization that traditional early intervention services did not necessarily meet the needs of families in which parents have special needs/mental retardation.

In 1988, Project CAPABLE, (Communities Assisting Parents to be ABLE) received a statewide outreach grant from the Handicapped Children's Early Education Program (HCEEP), U.S. Department of Education, to replicate this early intervention project in counties throughout Ohio. During the first two project years, Project CAPABLE staff have provided inservice training, ongoing technical assistance and replication services to over 800 service providers in the fields of early intervention, adult services for people with developmental disabilities, child welfare and children's protective services, medical services, advocacy protection and case management services.

This early intervention model, the Parent Infant Nurturing Group (PING) established at UACCDD, together with its underlying philosophy, forms the nucleus of this handbook which is a culmination of the last two years of field work by the Project CAPABLE staff.

The handbook is organized into five chapters:

**Chapter One: An Early Intervention Model** focuses on the underlying intervention philosophy and the basic goals and objectives of early intervention with families in which parents have special needs/mental retardation together with a description of the PING program.

**Chapter Two: Understanding of Parents with Special Needs/Mental Retardation** presents a checklist for initial identification and further understanding of parents with special needs/mental retardation.

**Chapter Three: Intervention Principles and Strategies** focuses on strategies and approaches to starting and successfully maintaining an early intervention program for families in which parents have special needs/mental retardation.

**Chapter Four: Evaluating Progress** describes an approach for early intervention programs examining changes in families in which parents have special needs/mental retardation.

**Chapter Five: Resources** offers an annotated listing of audiovisual materials, manuals, curricula, programs and a bibliography specific to parents with special needs/mental retardation.

# PARENTS WITH SPECIAL NEEDS/ MENTAL RETARDATION:

## A Handbook For Early Intervention

## Table of Contents

# CHAPTER ONE
# AN EARLY INTERVENTION MODEL

## The Philosophy, Goals and Objectives

"... it is not simply a matter of whether or not family needs are met, but rather the manner in which needs are met that is likely to be both enabling and empowering" (Dunst, Trivette, & Deal, 1988, p.4).

Early intervention for babies at risk of developmental delay with parents who have special needs/mental retardation requires heightened skills on the part of professionals to provide an environment which incorporates:

- a *proactive* framework based on the assumption that parents are competent or are capable of becoming competent;
- an ***enabling*** framework that focuses on creating opportunities for parents to exhibit competence; and
- an ***empowering*** framework that creates opportunities for meeting needs in ways that promote parents' sense of control over their own lives and those of their young children (Dunst, Trivette, & Deal, 1988).

"Special needs/mental retardation" was chosen by Project CAPABLE staff to include not only those parents who have been identified as mentally retarded through psychological assessment, school placement or other formal means, but also those who have been treated as if they were mentally retarded: i.e., the parent with a severe learning disability or cerebral palsy who was in classes for the "mentally retarded." The parents who inspired the development of Project CAPABLE have included parents with identified mild to moderate mental retardation and contributing conditions such as hearing impairment, mental illness, seizure disorders, substance abuse, cerebral palsy, and chronic poverty.

The Parent Infant Nurturing Group (PING) at the University Affiliated Cincinnati Center for Developmental Disorders (UACCDD) serves as an early intervention model for families in which the parents have special needs/mental retardation. The program focuses on the following **philosophical assumptions** that pertain to all parents of children at risk of developmental delay:

> ***Intervention should be family-focused and based on the family's identification of strength and needs.*** Early intervention must be flexible, accessible and responsive to the needs identified by the family. Intervention strategies should coordinate the child's developmental services with the physical and psycho-social needs of the child

and the family. Intervention services should be integrated into the family's daily home routine whether the child is receiving home or center-based services.

***Every family is unique.*** Family-focused intervention must consider an all encompassing view of the child and family: their interactions, their concerns and needs, and their strengths and limitations. The individuality of the child and his family, their different methods of coping, and their unique life experiences must be respected and supported.

***Each family is a unit that benefits from nurturance.*** Principles of nurturance apply to the entire family unit. Intervention strategies must include attention to parents' feelings of self-worth as well as the opportunity for clear, honest communication. The early intervention program should provide information about health, nutrition, child development, appropriate social roles, and linkages to community and personal support systems. Parents have a right to this basic information so that they can participate meaningfully in planning and decision making for themselves and for their children.

***Parents are the child's primary caregiver, nurturer, teacher and advocate.*** Parents and families are the constant in the life of a child. Professionals are transitory, dropping in and out based upon the condition, the complication, or the chronological age of the child. The parents best know their child's strengths and needs. They also best know themselves: their own strengths and needs. Consequently the parents are considered to be the team leader for the child's intervention program. Using professional persons as consultants for evaluation, therapy, materials and emotional support, the parents are enabled to fully implement intervention programs which have been jointly developed by themselves and the staff. Parents, educators and other professionals work together as equals on a team, contributing and accepting each others' thoughts and concerns.

***Intervention should occur early in a child's life.*** Brazelton (1990) expressed well the widespread belief: "We must begin early to enhance parents' desire to nurture" (p. 90). Children begin to learn at birth by attending and responding to selected stimuli. Children with or at risk for disabilities can benefit from early intervention as soon as they are identified in order to enhance their development and to prevent the development of secondary handicapping conditions.

***Every child has the right to optimum development.*** All children have a right to a life with caregivers who can facilitate their early development to its optimum potential. Professionals can help build on the strengths of the parents/caregivers and share with them the knowledge of what they can do to help their child reach those optimal levels of development. A child's early intervention program must address the total child through the family unit: their physical, intellectual, psychological and social development.

The following **philosophical assumptions** which are valid in all early intervention programs are emphasized in early intervention programs in which parents have special needs/mental retardation:

*The child belongs with the natural family.* It is every family' s basic right to raise the children to whom they have given birth; likewise, the children have a right to experience the natural love which parents have for their children.

*Every family has the capacity for competence.* Intervention strategies for families in which the parents have special needs/mental retardation should focus on opportunities for parents to increase self-esteem, social skills, and problem solving skills which will in turn enhance their ability to interact with their child. With appropriate community support, parents with special needs/mental retardation can increase their competence as caregivers and nurturers. The literature and experience show that parents with special needs/mental retardation can learn to be capable caregivers.

*Empowerment of the parents will create opportunities for meeting the child's and family's needs.* An early intervention program that creates opportunities for meeting identified needs will promote parents' sense of control over their own lives and those of their children.

*Effective intervention rests on parent-child interactions.* Development is best viewed as a constant process of reciprocal transactions between the child and his total physical and social environment. The early intervention program can promote development of effective interactions through 1) increasing the parent's and the child's sensitivity to each other's cues, 2) increasing the parent's and child's potential to respond contingently to each other's cues, and 3) increasing the parent's and child's mutual satisfaction with these interactions.

*Interagency collaboration is essential in a family's network of support.* A comprehensive system of early intervention includes a wide range of services for the entire family unit: parent(s), child(ren), and extended family. No single agency can meet all the needs of the entire family unit. Shared service plans and ongoing collaboration and involvement by multiple agencies are necessary to provide effective early intervention. However, the intervention should focus on building and strengthening networks of informal support for families rather than depending solely on the use of professional support systems (Dunst, Trivette, & Deal, 1988).

Based on these philosophical assumptions, **the goal of our early intervention program is to provide a family-focused, comprehensive early intervention program for children 0-3 at established, biological and/or environmental risk who have parents with special needs/mental retardation.** The concept of "group" is utilized as a service delivery vehicle to provide a built-in initial support system composed of both professionals and other families with infants who are developmentally delayed/disabled. The PING program views the infant-caregiver relationship as the most natural and effective basis for providing therapeutic intervention for the child, support and education for the caregiver, and intervention focusing on the relationship itself. The early intervention interdisciplinary team of parents/caregiver, specialists, and other community service providers works collaboratively to identify the family's strengths and needs, appropriate services to meet identified needs, and the most effective means for coordinating services.

**Primary objectives** of the PING early intervention program for families in which the parents have special needs/mental retardation build upon a family-focused philosophical base:

- *Growth in the **family/staff relationship:*** To establish a ***trusting partnership*** between families and staff which will enable families to understand that their experiences with professionals and their service delivery system can be rewarding rather than punitive;
- Growth in the ***family/child relationship:*** To enable families, through increased self-esteem, social skills, internal control, social role comprehension and problem-solving skills, to ***improve their parent-child interactions***;
- Growth in the ***family/continuity relationship:*** To build a ***collaborative network of formal and informal support***, in the realization that no one person/agency/organization is able to meet multiple, long-term needs of a family.

## The Program

The **Parent Infant Nurturing Group (PING)** at UACCDD is a center-based program that meets weekly for 1 ½ hours throughout the year. Each group is comprised of professional staff and five or six infants and their parents. The primary focus of the group meeting is the development of a relationship between the professional staff and the parents that is consistent, stable, comfortable and nurturing. The PING sessions therefore adopt a low key, informal style that allows for addressing issues as they arise rather than adherence to a "curriculum."

A "typical" session may consist of time spent one-on-one with families and members of the interdisciplinary team talking about individual family concerns or time spent as a group discussing feelings, shared experiences, or a topic identified as a priority by the families or the professionals (e.g., feeding, financial resources, community resources, support from own family members, language development). Cookie making, recipe swapping or seasonal craft projects also offer rewarding "group time" where everyone can comfortably share thoughts and concerns. One-on-one contact with the family varies according to the specific needs of the family and child. One family may talk with a therapist about speech concerns, another may work with the occupational therapist in developing infant holding techniques, another may talk with the early childhood specialist about "what their child is doing," while yet another parent may talk with a team member about concerns related to housing or finances.

An important part of the program is developing the accessibility of a collaborative network of community support services for families. In the informal setting of the weekly sessions and between sessions by phone, the team works with the family to promote increased self-esteem and problem-solving skills which utilize the available community network. The program views itself as "one piece" of this supportive network; this perspective results in ongoing collaborative contacts with all other agencies working with the family in order to build a unified network of services working together on behalf of the child and family.

The **professional staff** in the PING model consist of 1) a Program Coordinator who oversees all activities of PING, ensuring congruence of program activities with the program goal and objectives; 2) an Early Childhood Specialist who oversees the work of the interdisciplinary team and coordinates the day-to-day activities of the program; 3) an Early Childhood Associate who assists with the day-to-day program activities and follow-up; and 4) an interdisciplinary team consisting of a clinical nurse specialist, occupational therapist, physical therapist, a language specialist and a nutritionist whose roles can vary from that of direct service provider to consultant to other team members, based on the family's needs.

**Through the use of existing community and health services, the early intervention focuses on infants with or at risk of developmental delay and families at high risk due to environmental concerns.** The PING team refers to six criteria when assessing the appropriateness of including a family in the PING program for families at risk. The six criteria chosen indicate concerns regarding infant/child care and utilize information available from service delivery systems:

- one or both parents identified as having limited intellectual abilities (see Chapter Two, Figure 1);
- a significantly low HOME score (Home Observation for Measurement of the Environment, Caldwell, 1979);
- social isolation;
- history of neglect and/or abuse;
- history of psychiatric/substance abuse problems;

- significant lack of knowledge in such areas as child care, child development, and nutrition.

An evaluation of the first five years (1983-1988) indicated that the PING Program served 39 children in 30 families in which one or both parents were identified as having mental retardation on the basis of information provided by the family or referring agency. The average age of children at entry into the program was 11.3 months. The parents were married in 13 of the 30 families. The mean length of stay in the program for these families was 34.6 weeks. Follow-up data indicate that of these 30 families, 17 (22 children) are currently intact and are involved in services (e.g., Head Start program or being monitored by public health or social service agencies) ; five families have had their children (7) placed in temporary foster care but are working toward reunification. Eight children in six families have been permanently removed only two families have been lost to follow-up.

Initial contact with most families is made due to concerns about the child. Children at risk due to medical or developmental concerns are initially referred for evaluation to the Liaison Developmental Team (LDT) at the University Affiliated Cincinnati Center for Developmental Disorders (UACCDD). The Liaison Developmental Team consisting of a developmental pediatrician, the PING early childhood developmental specialist, a pediatric nurse, an occupational therapist, a physical therapist, and a nutritionist, may refer a family to the early intervention program following comprehensive assessment of the child and family. Reasons for referral include concerns regarding developmental delays, motor development, language delays, failure to thrive, neglect, and trauma due to prematurity. Parents are also referred to the early intervention program through public childrens' services such as the Department of Human Services and private organizations such as the Children's Protective Service. Some are remanded to the program by the court. Mothers are the primary participants in the program, although fathers are encouraged to attend whenever possible.

The PING team views the progress of the child as inseparable from the progress of the primary caregivers. Record keeping is designed for use as an historical review of information/staff notes and to assist staff in recognition of progress of child and parents. A system for observation of progress is presented in Chapter Four of this handbook. The process allows for a longitudinal view of parent-staff, parent-peer, and parent-child interactions that are believed to be indicators of progress. Observations related to parental (caregiver) interactions are recorded in the areas of self-esteem, social skills, internal control, social role comprehension, and problem-solving.

Use of the observation tools developed for the PING program are not intended to replace program information records on the developmental progress of the child, but rather to enhance the use of that information for the benefit of child, primary caregivers, and program staff. Observational records are used in connection with the Individualized Family Service Plan (IFSP) and development of family-focused goals.

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# CHAPTER TWO
# UNDERSTANDING PARENTS WITH SPECIAL NEEDS/MENTAL RETARDATION

"One letter haunts a distressing response to a column on support for mentally handicapped parents I am a teacher of developmentally handicapped children, largely indigent, because like begets like and their parents cannot hold an adequate job. It is not necessary for the handicapped to reproduce, nor is it fair to the offspring. They haven't a chance genetically or environmentally" (Kendrick, 1990).

A popular assumption has long existed that no person labeled mentally retarded can be an adequate parent. Early intervention practitioners working with parents with special needs/mental retardation are only beginning to understand their "competence. Because parents with mental retardation have not yet lived in the community for a full generation with adequate support to be parents, and because much of the literature includes only parents who have been court-referred due to abuse and/or neglect, many findings support stereotypes that may not apply.

"Mental retardation" refers to those parents with intellectual limitations, real and/or exacerbated by a lifetime of restricting opportunities. "Special needs/mental retardation" was chosen by Project CAPABLE staff to include not only those parents who have been identified as mentally retarded through psychological assessment, school placement or other formal means, but also those who have been treated as if they were mentally retarded: i.e., the parent with a severe learning disability or cerebral palsy who has been in classes for the "mentally retarded."

**The Literature.** Beginning with Mickelson in the 1940's, scientific studies have attempted to identify factors other than mental capacity which influence a person's parenting ability. Mickelson (1947) examined 90 families in which one or both parents were determined to be "feebleminded" and found that the parent's mental status did not appear to be the sole determinant of adequacy of child care. She later suggested that the capacity of the parents to respond to therapy and counseling had perhaps been underestimated and that service providers have an obligation to adapt their methods to meet the needs of the parents by utilizing community supervision and support (Mickelson, 1949).

One major difficulty has been that studies generally fail to separate the effects of mental retardation from the effects of living in poverty. One of the few studies which addresses the effects of mental retardation vs. poverty compares the decision making abilities of mothers with mental retardation with a control group of mothers with normal intelligence from the same socioeconomic status by utilizing descriptions of situations that place children at risk. No significant differences were found between the two groups (Tymchuk, Yokoto, & Rahbar, 1988).

A small but growing body of literature indicates that parents with mental retardation exhibit growth in competence in certain areas of parenting. One study used procedures such as discussion, modeling, feedback, and reinforcement to increase parental skills in praising appropriate child behaviors and imitating their child's vocalizations. Changes in the parents' behaviors were demonstrated which generalized to the families' home settings and were generally maintained over a follow-up period of 5-10 months (Feldman et al., 1986). In other studies, mothers with mental retardation not only showed gains in the empathy and warmth that they give to their children, (Tymchuk & Andron, 1988) but also learned a decision making process, showed increases in the appropriateness of their decisions, and have maintained gains in each of these areas during a situational follow-up (Tymchuk, Andron, & Rahbar, 1988).

The literature has identified factors which are helpful in predicting those parents with mental retardation who can provide adequate care for their young children: an IQ greater than 50, being married, having fewer children, reasonable financial support, and adequate support from formal/informal sources which is accepted by the family (Tymchuk, Andron, & Unger, 1987). The parallels between these factors and those protective factors that promote positive outcomes identified in the thirty-year Kauai longitudinal study of high-risk infants are striking (Werner, 1988): what emerges is a pattern of support for parents with or without mental retardation, ranging from spouse to family to friends to professionals to other community resources. The importance of support for families in which parents have special needs/mental retardation and for all families who have young children at risk is well recognized (Bromwich, 1985; O'Neill, 1985; Whitman, Graves, & Accardo, 1987; Attard, 1988; Abraham, 1989; Deal, Dunst, & Trivette, 1989).

**Identification and Understanding.** Early intervention programs may find it helpful to consult the "Checklist for Identification of Intellectual Limitation in Parents" (Kaminer & Cohen, 1983) seen in Figure 1 on page 11. The checklist is helpful, not to label and categorize parents, but to identify the dynamics of parental behaviors that are often misinterpreted by professionals and others. If at least five out of the first nine behaviors on the checklist are exhibited on a regular basis or if parents are identified by information available as described in item ten, then it is likely that the parent has intellectual limitations that may impact parenting. The checklist is helpful in identifying those who may benefit from intervention by describing in observable terms those parents about whom we are concerned.

Figure 1

## Identification Checklist
## For Identification of Intellectual Limitation in Parents

Ruth Kaminer, M.D.; Eleanora Jedrysek, M.A.; Bee Soles, M.S.W.
of the Rose F. Kennedy Center, Albert Einstein College of Medicine

1. Cannot travel alone on public transportation; always comes to clinic accompanied by another adult.

2. Reading and writing problems seen when filling out application:

   a. unable to write
   b. writes minimal factual information only
   c. reads words but with very limited comprehension

3. Erratic appointment keeping (early, late, odd excuses, wrong day).

4. Provides vague or naive information about basic facts.

5. Problems managing money.

6. Overwhelmed by routine demands.

7. Child management difficulty of excessive degree observed or reported.

8. Uses covering-up techniques to conceal deficit.

9. Central role of a "benefactor"; requires help in areas not expected for adult.

10. Historical information documenting limitation/retardation from:

    a. self-report
    b. family member
    c. social agency

Kaminer, R., & Cohen, H. (1983). Intellectually limited mothers. Developmental handicaps: Prevention and treatment (p. 42). Washington, DC: AAUAP.

(Ed. note: This identification checklist is offered as a guide to identify the dynamics of the behaviors of parents. If at least five out of the first nine behaviors are exhibited on a regular basis or if parents are identified as in item ten, it is likely the parent has intellectual limitations that may impact parenting.)

Five areas of functioning are key to looking for ways to better understand the behavior of parents with special needs/mental retardation: 1) Self-esteem; 2) Social skills; 3) Internal control 4) Social role comprehension; and 5) Problem solving skills. These five areas can have a significant effect on parenting.

Self-Esteem. Healthy self-esteem is closely related to social adjustment and to acceptance of the responsibilities of parenthood. Because segregation and frequent failure (both academic and social) may have been primary to the learning experience of adults with mental retardation, self-esteem is likely to be damaged. Continued rejection can cause the development of bitter, hostile and anxious feelings which may result in an adult who is self-deprecating and has severe difficulty relating to and being close to others. Recognition of accomplishments is vital to the development of self-esteem. It seems significant that praising has been found to be the single most lacking maternal behavior exhibited by mothers with mental retardation and that the absence of praising behavior is tied to low self-esteem on the part of the mothers (Feldman et al. , 1986; Peterson, Robinson, & Littman, 1983; Tymchuk & Andron, 1988). Building parental self-esteem must be recognized as primary in providing early intervention services to parents with special needs/mental retardation.

Self-esteem is enhanced as parents experience success in managing difficult situations; this can start with learning to make simple choices. As we strive to assist parents with their perceptions of themselves through our interactions with them and to provide opportunities for meaningful contributions to occur, self'-esteem grows. Through recognition of the unique and creative ways parents in different life circumstances solve their problems, development of mutual respect occurs. For example, a mother in Cleveland, Ohio, solved the problem of having no kitchen table by spreading newspaper on the floor and assigning the children a spot "around the paper." We can react with dismay that this family is eating on the floor or promote self-esteem and mutual respect by recognizing that this mother has established a mealtime routine and solved a problem in a reasonable way given her resources. It is our job to recognize success where we see it rather than to redefine it in terms which may inhibit the self-esteem and dignity of the families we strive to serve.

Social Skills. Acceptable social skills for parents with special needs/mental retardation are essential to the task of parenting. Parents who know how to access services, talk to professionals, and ask the right questions are considered by those who serve them to be interested, adequate parents. Social skills of adults with special needs/mental retardation may be limited in scope due to lack of social interaction and contact. Because expectations for people with special needs/mental retardation have been very limited, even those individuals growing up in nurturing families may have been socially isolated. Parents with mental retardation have not been taught to seek out needed services and, for the most part, have no experience in voluntarily consulting with "professionals"; they are "taken to" services or have had services brought to them. Modeling successful social interaction is vital to development of social skills that will enable the parent to access what is needed for them and their child. For example, a mother in Cincinnati, Ohio, indicated that she wanted books for her children. Instead of buying books or giving or lending books to her, an alternative strategy was developed. By providing access to the public library, by assisting her in applying for and acquiring a library card, by showing her how to check out, return books and how to interact with the library staff, she was empowered to gain for her children and herself what she had determined was needed.

Development of social skills depends on opportunities to communicate, to listen, to learn, to share and negotiate in natural surroundings so that natural rewards and consequences are experienced. Parents may choose to be isolated in order to "pass" as normal or because they are uncomfortable and unsure of their skills in even the most simple social interactions. Those opportunities that focus on a task that is "fun" and non-judgmental can be the beginning of increased social competence. For example, making a simple toy or cutting up fruit for a snack with other mothers focuses on a task but provides rich opportunity for social skill development.

Internal/External Control. Many adults with mental retardation have been taught through use of external control methods. Response, not reasoning, has been the mainstay of many special education programs (Turnbull & Turnbull, 1985). Self-direction, internalization of reward and the value of appropriate human interaction may not have been part of the individuals life experience. Many techniques used to control or change behavior, especially of institutionalized individuals, have been punishing rather than rewarding and, consequently, the reward of human presence and interaction has not been taught. "We learn the meaning and value of a person's presence through our reciprocal interactions... if the presence of either or both persons participating is perceived as noxious or meaningless, it is likely that the interaction will be terminated or will become maladaptive" (McGee, Menolascino, Hobbs, & Menosek, 1987, p. 44). It is difficult to perform the many routine tasks of parenting if one only responds to external "reward." Parenting in and of itself is often a "giving" task that results in no immediate tangible reward. The adult who has been excessively controlled or coerced as a child may as an adult passively submit or rely to an excessive degree on direction of others--thereby ignoring cues from her own child. It is also feasible that ignoring the task at hand, forgetting, procrastinating and daydreaming will be part of the adult's life style (Marlin, 1976). If we persist in treating people with mental retardation as children, then their response to parenting is likely to be childlike. However, if we begin to ask the parent to make choices, to assist them in gaining control by understanding their behaviors and those of their child, and to support their decision making, we are establishing that the parent is a responsible adult.

Social Role Comprehension. The roles of independent adults and parents are certainly very new to the adult with special needs/mental retardation. Those who are adequate parents have generally learned those skills from their parents. We teach our children "good parenting" in a very natural way since we suspect that they may as adults be parents, too; if that is not, nor never has been, the expectation, not much attention will be paid to the task. For the most part, regardless of where adults with special needs/mental retardation have grown up (loving home or institution) , the issues of sexuality, parenting and social role development have not been addressed.

Little attention has been given to what the "roles" of people with mental retardation might be. We don't ask children with mental retardation what they want to be when they grow up. Social roles develop through opportunity to explore the roles of adulthood. Since many parents with special needs/mental retardation have not had those opportunities, it is important to assist them in understanding what being a parent means and to support them in that role by recognizing that they may do the wrong thing for the right reasons. For example, the father who spends all his money on expensive toys for his child rather than on basic necessities may think that he is being a good father based on his perception of what good parents do. His perception may be based on advertising promotions or on what he sees other parents doing. The father will not understand the role of a parent as one of protector who knows how to balance needs with desires unless specific attention is directed toward the development of this perspective.

Problem-Solving Skills. It is now recognized that people labeled as mentally retarded are perhaps the last of various client groups to be considered autonomous individuals with a say in their own destinies (Abraham, 1989). If they are to have a "say", problem solving skills must be addressed. While volumes of information exist to teach individuals with disabilities academic and technical skills, there is a "dearth of curricula for teaching students how to pinpoint and define problems, generate and evaluate alternatives, select the preferred alternative, take action, and evaluate the consequences of their action" (Turnbull & Turnbull, 1985, p. 116). It is unrealistic and unfair to expect adults with special needs/mental retardation to solve the multiple problems related to adequate parenting without recognizing and addressing the issue that they have not been taught problem-solving skills. Although it has generally been assumed that adults with special needs/mental retardation cannot be adequate parents, we are just now beginning to recognize that necessary skills for parenting have neither been considered nor taught.

By addressing behaviors in these five areas of functioning, we gain a better understanding of parents with special needs/mental retardation as they interact with their child and others. A foundation for mutual respect emerges as we take a positive approach and assist the parent in identifying strengths and needs. It is in the context of such a relationship that meaningful services can be delivered to the child and her caregivers.

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# REFLECTIONS OF INTERDISCIPLINARY EARLY INTERVENTION TEAM MEMBERS WHO HAVE WORKED WITH PARENTS WITH SPECIAL NEEDS/MENTAL RETARDATION.

The development of Project CAPABLE's early intervention model evolved over a period of five years and involved the ideas and talents of many people. An important feature of this early intervention model is the interdisciplinary team working with each family. Each member of the team brings to the relationship their years of training and experiences. They <u>may</u> also bring negative stereotypical opinions about families that could inhibit their attempts to form a partnership with parents with special needs/mental retardation. The individual team members <u>may</u> have difficulty in implementing a model of service delivery that requires adaptations so that families can benefit from their services. Very few professionals have been prepared for the challenges presented by parents with special needs/mental retardation. Yet, with experience, they have developed the skills necessary to work with them effectively. Presented here are the thoughts, ideas, and suggestions of the professionals who have worked with the Parent-Infant Nurturing Group (PING) of the University Affiliated Cincinnati Center for Developmental Disorders from 1983-1991. Interviews were conducted with fourteen former and present PING staff members whose disciplines include early childhood special education, speech and language therapy, psychology, nursing, nutrition and occupational and physical therapy. They have had varying levels of involvement, ranging from being present at every program session and performing all the follow-up activities to coming to PING only once a month.

### "How did you feel about parents with special needs/mental retardation before you began working with them?"

The replies to this question ranged from not knowing anything to never knowing a time when they were not working with parents with special needs. Several worried that the parents would not ever be capable of raising their children. A psychologist thought parents with special needs/mental retardation would have problems with child rearing (especially with judgment choices) not faced by typical parents. A clinical nurse specialist/service coordinator said that she felt the information she was giving parents was not meaningful to their day-to-day lives. A nutritionist thought the parents would have a lot of needs and she was astonished to find that they had many more needs than she had imagined. The present coordinator of early childhood programs felt that although she had always worked with parents with special needs/mental retardation, she thought that not very many people with "limited intelligence" had children. The former PING program coordinator said that one mother in an early intervention group for children with handicaps or developmental delays was enough to convince her that a group should be created to provide services to high-risk families. Most simply did not know what to expect from the families.

After working with parents for a period of time, perceptions changed positively in ways that were dramatic, even for staff members who were not "skeptical" prior to working with parents with special needs/mental retardation. The consensus of opinion was that the parents did have strengths and could succeed as parents. One response was that individual strengths and needs were similar to those of "normal" parents and were rarely related to IQ. A psychologist continued to have mixed feelings about the parents being able to be "good" parents but she did not feel that either special needs or mental retardation were deciding factors in effective parenting. She felt that background and motivation are more significant to a parent's success; some parents did a good job with support while others did not. A registered nurse was "frankly surprised" that the children were thriving and that the parents came to PING consistently. One speech pathologist noted that she became less judgmental and accepted a much broader view of appropriate parenting. Her respect for parents with special needs/mental retardation grew as she came to realize that often they did more with the resources available to them to help their children reach their potential than typical parents do. A nutritionist found that a mother's ability to provide adequate nutrition was closely related to her own self -image, making the professional's job more than merely offering nutritional advice for the child. An early childhood special educator said that, like all parents, these parents want the best for their children and if they have support, they can get it. In fact, this teacher and her program assistant have found that parents with special needs/mental retardation have better attendance records and are more interested in the program than the more typical parents whom they serve. Another early childhood special educator made the point that not all parents with special needs/mental retardation can be good parents but, with support, some can be. An occupational therapist said that although she has worked with parents with special needs/mental retardation for a while, she still cannot begin to understand how they feel. The program coordinator also commented that these parents need on-going programming unlike the short-term programs offered to typical parents.

### "What kind of adjustments, if any, did you have to make in the way you offer and deliver your services?"

A speech pathologist said that she had always used a therapeutic approach with other families and their children that did not include the parents to any degree. In working with families in which a parent has special needs/mental retardation, she stated that she now works more with parents to show them what she is doing with the child. Using simple and concrete examples she shows parents during conversation the next step that they can do with their children while playing with them. An occupational therapist found that she is now treating the whole family, not just the child. Most mentioned that they ask the parents what concerns them about their child and this becomes the basis for "therapy."

Another occupational therapist confessed that she is still struggling with adjustments and finds herself being more instructive and directive than she would like to be. Her time constraints force her to be less involved than other team members in the program so that she has little opportunity to form relationships with parents. She works at taking into account the whole person and their environment and life situation. A psychologist commented that rather than working on relationship building she has had to work on detaching herself from families at times. She has to accept how much she can change and what she can not. Adjustments are also necessary in the presentation of information for those accustomed to working with "middle-class" parents, i.e., those parents who understand information easily, carry out suggested activities, and have adequate resources to meet their families' basic needs.

**"What are some recommendations you would make to those in your field about working with parents with special needs/mental retardation?"**

The overwhelming response was to re-define: success, structure, expectations and service provision. The former program coordinator urged that programming should be seen as a long term process: "You have as much to learn from them as they do from you." A special educator pointed out that the relationship with a family, so very important to effective early intervention, can take a long time to develop with parents with special needs/mental retardation. A sense of humor was mentioned by several respondents as being important in facing many situations. A number of professionals from the different disciplines all said that an understanding of the families' environments and their socioeconomic situation goes far toward promoting better understanding of the actions and behaviors of parents. A physical therapist also recommended that it was very helpful to her to have a background in the area of dual diagnosis (mental health and mental retardation). An early childhood educator warned educators "not to be too idealistic: these families will never be the Keatons on 'Family Ties'". A program assistant commented that she felt more competent when working with parents with special needs/mental retardation as they were often more comfortable with her than with other staff members, at first, because she did not have a degree and a title. A speech pathologist said that she let go of her own standards of behavior and preconceived notions of "good" parenting. She said that one "cannot be critical or judgmental when you haven't dealt with [the parents] limitations." She considered their limitations to be not only intellectual but environmental as well. A nutritionist had an interesting way to discover the feelings of parents when she had to ask them very personal questions; she asked good friends how they felt when asked the questions. In this way she was more able to put herself in the parent' s place and thus build a relationship. Capturing the mood of many of the respondents, another speech pathologist said that "you have to be able to sit down with a parent and put your arm around her if she needs it."

Some final words of advice came from a clinical nurse specialist/service coordinator and a former program coordinator; both said not to be afraid to work with parents with special needs/mental retardation. Progress may need to be measured differently, but it can and does occur. Processing and discussion time after each program session are very important to ensure that responses to parents' needs are helpful and empowering. Several of those interviewed recommended that professionals need a lot of experience working with all parents before working exclusively with parents with special needs/mental retardation. One comment was that one needs "street smarts" to be able to provide the supports that parents need. Keeping an open mind to the needs of parents makes it possible for the families to have good experiences with programs and professionals. In the end, as one respondent said, "It is gratifying to see them succeed and be good parents."

# CHAPTER THREE
# INTERVENTION PRINCIPLES AND STRATEGIES

The success of any early intervention program strongly depends on a philosophical model and subsequent administrative, programmatic, and staffing decisions that reflect that model. The concept of empowerment may create conflicts for staff working with parents who initially may not appear competent or even capable of becoming so. **The Primary Objectives** of the early intervention program for families where the parents have special needs/mental retardation have inspired corresponding program principles and strategies for implementation of a model of empowerment.

**Objective I: Growth in the family-staff relationship:** To establish a trusting partnership between families and staff which will enable families to understand that their experiences with professionals and their service delivery system can be rewarding rather than punitive.

**Principle One: Program has identified relationship-building as its primary initial goal.** Establishing a trusting relationship with parents with special needs/mental retardation is the key first step in providing early intervention that will have a positive impact. Providing concrete assistance to families in response to identified needs can facilitate this process; however, this strategy alone does not guarantee progress or success. Many parents with special needs/mental retardation may initially present themselves with overwhelming needs for assistance; on the other hand, many parents with special needs/mental retardation, like the multi-risk families described by Greenspan (1990), may be skillful at manipulating and/or avoiding offers of assistance. Greenspan contends that the establishment of trusting a relationship is "absolutely necessary" and "must provide regularity, an emotional attachment, and a process that facilitates the description and examination of interpersonal patterns" (p. 162). For parents with special needs/mental retardation, it is the trusting relationship that provides the context for growth in self-esteem, social skills, internal control, social role comprehension and problem-solving. Recent research supports the premise that building a relationship, particularly with a parent with low social skills, results in improved parenting skills that impact positively on the infant's development (Booth et al, 1989).

Such a perspective can pose challenges for professionals who have been trained in a traditional child-focused rather than a family-focused approach to early intervention. Professionals may feel that their skills are being underutilized or wasted, and thus will resent the time and effort needed to provide support and affirmation - especially as it often reaps minimal immediate results. However, it is unlikely that priorities can be shifted toward parenting and child development issues until this primary goal has been at least partially accomplished. Indeed, evaluating progress toward this goal can become one strategy for measuring "success" of both the program and individual families.

Viewing the parent-professional relationship as primary has distinct implications for program policies. For example, it is crucial to support families' attendance in a variety of ways: collaborating with other agencies to assist with transportation, following up to show your concern when families do not attend, or not using poor attendance to eliminate families from program participation. In fact, families' improving attendance can be an indication that the program is effectively addressing the goal of relationship building, while "poor" attendance may signal the need for a program to reexamine its goals and objectives.

**Strategy 1: Staff have sufficient skills in relationship-building and empowerment for parents with special needs/mental retardation.** The building of partnerships with parents with special needs/mental retardation can be initially facilitated through (1) focusing on needs most crucial to the parent, and (2) being nonjudgmental and affirming while providing appropriate assistance. However, one of the skills that is most difficult in working with families with special needs/mental retardation is to help families identify priorities that are important to them. "Doing for" is a common mistake that we must guard against. For example, consider a mother referred by the court who initially presented the picture of "I am a fine mother, thank you, I have no needs, and I don't want to be in your program." A student making a home-visit happened to notice that there were no toys available for the baby; when asked about this, the mother responded that the toys had been stolen. From this conversation, the mother acknowledged that toys were something that she was interested in for her baby, and "toys" became the primary goal for her because it was something that was important to her. This priority fit very nicely into an overall program goal of improving interactions between the parent and child, and the building of a partnership started with assisting the mother to make toys that she could use with her baby.

Brechin and Swain (1988) propose alternatives to the traditional client-professional relationship which have implications for the ways in which professionals' might support parents with special needs/mental retardation:

- ***Learning to know and enjoy the parent***
- ***Learning to be on their side in seeing problems***
- ***Expressing a belief that the parent is worthwhile***
- ***Demonstrating a commitment to the parent***
- ***Accentuating the parent's positive qualities (i.e., strengths)***
- ***Monitoring one's own communication***
- ***Enhancing the parent's mastery and control***
- ***Assisting the parent without control or power***
- ***Sharing skills and information***

If the early intervention professional can employ these skills, the result on behalf of the parent with special needs/mental retardation is growth in self-esteem, social skills, internal control, role comprehension, and problem-solving. Brechin and Swain (1988) make a final key point in creating a partnership: the primary concerns should be "the process of traveling, and the nature of the relationship generated on the journey" (p. 224). To view early intervention with parents with special needs/mental retardation as a "journey" can serve to minimize frustration when progress does not seem to occur quickly or easily, for it is within the partnership journey that "progress" will take place.

**Strategy 2: Program has refined the intake process to eliminate waiting lists and unnecessary paperwork.** Waiting lists and paperwork are two of the greatest obstacles to successful participation in early intervention programs by parents with special needs/mental retardation, and reflect the concept that the "system" can be disabling in and of itself. The 45-day time period from date of referral to the development of the IFSP as contained in P.L. 99-457 may help to minimize this barrier; the more quickly families can begin services after being referred, the less likely they are to disappear and subsequently be labeled "hard-to-serve" or "resistant." If families cannot begin a program immediately, program staff should maintain regular and frequent contact with the family and/or referring agency in order to maintain the linkage established by the referral.

Paperwork must be reduced to that which is absolutely essential; failure to complete forms should not be used as a justification for excluding families from services. It is critical to understand that most forms typically require a level of reading and writing not attained by many parents with special needs/mental retardation. Rather than admit this "weakness," families may "lose" the papers or offer multiple excuses for failing to complete the forms. It may be necessary for staff to sit down with the family and ask, "Can we fill this out together now?" Such an offer, if made in a nonjudgmental and supportive way, can provide the family with an opportunity to experience dignity and control.

Another strategy that has been helpful to families is the concept of the "Family Child Journal" (Beatty, 1990), an example of which in seen in Figure 1 on page 24. Every family needs a way in which to keep records concerning their child: i.e., birth, development, medical, school and therapy records. The Family Child Journal offers the family a method for keeping those records in an organized manner. The loose-leaf design of this book allows a family to maintain and share individual sections of information concerning their child and family according to their needs and the needs of the professional with whom they are working. The first four chapters contain information needed by professionals with whom a family comes in contact. The additional sections contain more in-depth medical, school, nutrition and birth information. The book is designed so that the professional can offer to help a family complete the portions they wish to use. The separate sections are picture-keyed to help the parent with special needs/mental retardation identify section contents.

Figure 1:

## *FAMILY CHILD JOURNAL*
## TABLE OF CONTENTS

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Today's Date____________
Updates____________

### I. HOME, TELEPHONE, & TRANSPORTATION ABOUT YOUR CHILD

Child's name______________________________ Birthdate____-____-____
Birthplace________________________ Child's Social Security #_____-___-_____
Birth Certificate #______________ Sex_____Male_____Female
Living Address______________________________________________
Street City State Zip
School District______________________
Address during day if different______________________________
Child is usually cared for during the day______________________
(e.g. Daycare, Baby sitter, Relative) Name Phone

### ABOUT YOU

Your Name______________________________________________
Address______________________________________________
Street City State Zip
Telephone______________ ______________ ______________
Home Work Other/None

Are you this child's birth mother, birth father, adoptive mother, adoptive father, legal guardian, sister, aunt, grandmother, foster mother? Please circle all that apply or write in this space:

______________________________________________

If you are not legal guardian, please provide their name & address:

______________________________________________

Languages spoken in the home______________________________

### TRANSPORTATION

Do you travel by bus?_____ you drive?_____ someone else drives?______________
Red Cross?_____Access?_____ Is travel a problem for you? Yes_____ No_____
Please explain if travel is a problem for you:______________________________

______________________________________________

**Strategy 3: Families in which parents have special needs/mental retardation are assessed in a way that identifies their strengths and needs in an appropriate, nonjudgmental, supportive manner.** P.L. 99-457, Part H, states the following guidelines for family assessments:

- Family assessments must identify needs and strengths;
- Family assessments must be voluntary on the part of the family;
- Family assessments must be conducted by trained personnel, utilize "appropriate" procedures, include a personal interview, and incorporate the family's description of its strengths and needs.

A recent article (Summers et al., 1990) that examines family preferences in the process of developing the IFSP stresses the "uniformity of opinion about the importance of informal methods to gather information required to develop the IFSP" (p. 86). "Informal methods" were characterized by "conversations" rather than structured interviews, non-intrusive questions, keen listening skills, and a willingness to spend time developing rapport. Such a procedure for family assessment is most likely to be the most "appropriate" for parents with special needs/mental retardation as well.

Many parents with special needs/mental retardation may view early intervention to be intrusive because they have been referred due to problems with them rather than with their child. Standardized family assessment measures are often intimidating to the most educated and articulate parents, let alone a parent with limited verbal, reading and writing skills. Consequently, the use of such forms can be an obstacle in and of itself.

The concept of a "conversation" with a parent with special needs/mental retardation as the procedure for family assessment creates the opportunity for the beginning of a productive, trusting relationship. If we can gather information through interaction, through observation , and through listening, then we also have a better chance of gathering the most accurate information as well. Such a conversation may not be accomplished in just one session; several meetings may need to occur before some parents will respond with more than a nod of the head or a simple "yes" or "no." Again, it is crucial to view these meetings as the beginning of a journey, rather than an end product. For many parents with special needs/mental retardation, family assessment is likely to be an ongoing process throughout their involvement in a program, for the more they trust a professional or program, the more likely they are to share what is really important to them. A parent still sharing "needs" twelve months into a program can be viewed as program success, rather than as a program's failing to address all the needs of the family.

Using a conversational approach to family assessment does not preclude the use of standardized forms to guide the conversation or record that information (preferably after the fact rather than in front of the family). One tool that may be of particular assistance is the Inventory of Social Support

(Trivette & Dunst, 1988). The second part of this inventory contains a list of twelve questions that are phrased in language that "makes sense" to families: e.g., "Who hassles with agencies and individuals when you feel you can't get what you need or want?", "Who keeps you going when things get hard?", and "Who loans you money when you need it?". Nineteen sources of support are listed, ranging from "myself" to "spouse" to "friends" to "church" to a variety of agencies. The resulting matrix is helpful, not only in the initial family assessment, but also in guiding the development of an adequate support system which is crucial to the ultimate success of these families.

**Strategy 4: Program orients families in such a way that families have input and decision-making opportunities.** The very first contact with a parent with special needs/mental retardation can lay the foundation for an enabling relationship. The initial phone call or the initial letter (which parents may not be able to read -- or, if they can read, they may not be able to comprehend due to professional jargon) can inadvertently be yet another in a long series of negative encounters with professionals. Professionals should consider that every contact, no matter how short or inconsequential, conveys a message to parents. Wherever possible, parents should be given the opportunity to begin making choices and establishing control over their lives, such as:

> "Would you rather visit our program first or would you like someone to visit you in your home?"
>
> "What day and time would work out for you?"
>
> "Do you want to fill out this form or should we do it together?"

**Strategy 5: Program activities are based on jointly identified family strengths and needs.** It is important to focus on the intent of P.L. 99-457, that "intervention efforts should be based on family-identified needs and aspirations in order to have the greatest positive influences on child, parent, and family functioning" (Deal, Dunst & Trivette, 1989, p. 34). Parents with special needs/mental retardation can identify priorities for themselves and their children within the context of a safe, trusting, enabling relationship. For many of these families, it is likely that initial "needs" will be perceived by professionals as family-focused rather than child-focused. For example, some families may identify a need for new housing or food or jobs or even diapers to last them through the month. Dunst, Trivette and Deal (1988) identify twelve categories of needs, only two of which specifically pertain to the child; their work suggests that before parents can devote their efforts to work on what we professionals traditionally have recommended (i.e., child-focused interventions), effective early intervention must focus on helping families meet their other needs. "The greater the number of needs unrelated to child-level interventionists, the greater the probability that the parents indicated they did not have the time, energy, and personal investment to carry out such interventions" (p.20). These results cut across parents' age, education, and socio-economic status.

In focusing on jointly identified family strengths and needs, a clear demand for interagency collaboration becomes evident. No one program can meet the multitude of needs expressed by families in which parents have special needs/mental retardation. Given the ever increasing demands on staff time and program resources as we move toward a family-focused perspective, the only logical solution is that of collaboration among the wide variety of services that may be necessary.

**Principle Two: The approach to working with parents with special needs/mental retardation is consistent with all other families served in your early intervention programs services.** Although parents with special needs/mental retardation may require some adaptations, the approach to their early intervention program should be consistent with early intervention being provided for all other families. In order to avoid perpetuating the concept of segregation of persons with special needs/mental retardation, it is crucial to view working with the families not as a separate entity, but as part of the entire early intervention program. Although many programs have expressed their inability to serve parents with special needs/mental retardation effectively in groups or classes with "middle-class" parents, we do not advocate a separate program just for parents with special needs/mental retardation. Rather, these parents are struggling with the same issues as certain other parents, e.g., those who have had limited educational opportunities and parents who are involved with multiple social service agencies. Although the strategies and length of time to accomplish goals may vary, for all families the concept of empowerment is valid. Even when early intervention is delivered to parents through an agency serving only adults with special needs/mental retardation, a key program goal should be to assist these parents to become part of their community through a network of formal and informal supports.

**Strategy 6: Program has a written statement of its philosophy/theoretical approach to early intervention with parents with special needs/mental retardation.** It is crucial for any organization to develop and record its philosophical approach to working parents with special needs/mental retardation. From our perspective, the model of empowerment holds the most promise for success for parent, child, and professional, for it provides opportunities for parents to make gains in self-esteem, social role comprehension, social skills, internal control, and problem-solving. These gains will ultimately impact on their relationship with their child and the larger community.

**Strategy 7: Program has defined programmatic goals and objectives for early intervention with parents with special needs/mental retardation.** Choosing the philosophical model of empowerment for parents with special needs/mental retardation has distinct implications for choosing program goals and objectives. For example, programs which focus strictly on the child and do not view responding to needs of the parents or interagency collaboration as important program objectives are likely to experience frustration and failure in working with parents with special needs/mental retardation objectives which are more likely to drive an effective program are those described in Chapter One:

- to establish a trusting partnership between families and staff;
- to enable families, through increased self-esteem, social skills, and problem-solving skills, to obtain improved parent-child interactions;
- to enable families to understand that their experiences with professionals and the service delivery system can be rewarding rather than punitive;
- to build a collaborative network of support and services, in the realization that no one agency has the staffor financial resources to meet all needs of all families; and
- to support the successful transition of families to community based services, with the recognition that these families may need to access a long-term consistent support system.

**Strategy 8: Staff display warmth and respect toward parents with special needs/mental retardation.** "By far the most important factor that contributes to the success of a parent with special needs/mental retardation is the attitude of those with whom they interact" (Tymchuk, 1990).

Partnerships with parents who have special needs/mental retardation are built upon the foundation of values and attitudes. If we value equality and the integrity of parents, then we will view our role as one of guides, not "gods," who assist families as they identify their needs and provide support and assistance to enable parents to discover the solution. "Professionalism" which decides what people need and "how-to-fix-it" can be disabling in and of itself, whereas "partnership" connotes sharing; as professionals we do not have nor should we suggest that we have all the answers.

A trusting relationship of mutual respect may take months to develop with parents with special needs/mental retardation. It is important to consider the many and subtle ways that respect can be conveyed, e.g., picking up a child only after asking the parent's permission. We often fail to consider the unintentional consequences of our comments and actions, particularly when interacting with parents who at first glance present more "needs" than strengths. One home-based early interventionist related an incident in which she visited a mother with special needs/mental retardation and her several young children and noticed that the family had no kitchen table and chairs. Rather than commenting immediately on this "deficit," she observed how the mother handled mealtime: the mother spread a clean newspaper on the floor, helped the children to their "assigned seats, and invited the early interventionist to join them. The early interventionist later recalled that if she had remarked upon the need for a table and chairs, the mother might have interpreted this as a criticism of her home and her ability to care for her children. Instead, the home interventionist commented positively on the mealtime routine that this mother had established, which opened the door to a trusting relationship.

It is often easy to assume that persons with special needs/mental retardation do not have insight into their own feelings or the capacity to interpret implications of statements by others. However, as stated by an adult with special needs/mental retardation, "I may be retarded, but I'm not stupid."

**Strategy 9: Staff have clearly defined roles and responsibilities.** Professionals may have to "rethink" their role in view of what we propose as an effective intervention model for parents with special needs/mental retardation. What emerges from trying to define roles clearly is not role narrowing, but rather role expansion and flexibility. For example, many professionals may struggle as they feel they are "wasting time" if not imparting information to a parent. However, to confine oneself to sharing skills and information, which is the traditional role of an early interventionist or therapist, limits the potential for an effective partnership with a parent. As one of our therapists so aptly stated: "It's hard to remember that a parent won't care if her child is walking or not if the landlord has turned off the heat or if she's run out of food."

In thinking about all the roles implicit within partnership building and empowerment, one inevitably encounters, "It's not in my job description." Opportunities for increasing trust and empowering the parent with special needs/mental retardation may not fall within a rigid job description. For example, a mother in the program called the staff because she was apprehensive about a scheduled medical visit for herself; she had missed a previously scheduled appointment due to her fear and reluctance to go by herself. Although meeting the parent at the hospital for the test was not within the traditional boundaries of a center-based program, the staff juggled responsibilities in a way that freed one staff member to respond to the need for support identified by the mother. The ultimate impact upon this mother was made evident several weeks later, when she volunteered to accompany that professional who happened to be scheduled for the very same test- so that she, the parent, could "return" the support provided her. Clearly, it is imperative that programs spend time defining roles and responsibilities -- and enlist the support of the entire team and administration, for it is likely that "traditional" roles will be tested by the journey toward partnership with parents with special needs/mental retardation.

**Strategy 10: Sufficient time for planning and discussing sessions and family contacts has been built into the program model.** Working with parents with special needs/mental retardation will prove to be a lengthy and sometimes exhausting process. Given the time and financial constraints of most programs in the 1990's, planning time is often one of the first activities to be cut. However, without this time, small steps of progress by families can easily be missed.

In one program, for example, a mother with special needs/mental retardation was working on a project that required use of scissors. The staff handed the mother right-handed scissors. A videotape made of the session later revealed that the mother was left-handed. She had not asked for left-handed scissors, but with much difficulty, accomplished the task at hand. Staff was embarrassed that this obvious characteristic had been overlooked, apologized to her and provided left-handed scissors for the next project. Relationships of parent and staff can survive much more critical mistakes then incorrect scissors, but planning time prior to service delivery and discussion time with all participating staff following service delivery can make an important difference in carefully thought out service that addresses individual needs as much as possible.

**Objective II: Growth in the family/child relationship:** To enable families, through increased self-esteem, social skills, internal control, social role comprehension and problem solving skills, to improve their parent-child interactions.

**Principle Three: The staff should have sufficient knowledge about parents with special needs/mental retardation as adult learners.** Understanding the behaviors of adults is an important consideration of effective early intervention with parents with special needs/mental retardation. As we learn more about these parents, we come to appreciate that many of their "deficiencies" really stem from services in systems where problem-solving, social skills and self-esteem have not been addressed. (See Chapter Two).

**Strategy 11: The staff should have an understanding of adult learning theory.** It is important to keep in mind basic tenets about the way in which adults acquire and accept new knowledge. Adults as learners differ from children in several important ways:

- The adult learner is influenced by how he sees himself. Adults will not want to be treated like children or to be "talked down to." Adults want to be self-sufficient and expect to be in charge of their own actions. Respect of an adult's opinions are very important to him. However, the adult may not have been in a learning situation for some time and may need encouragement to feel comfortable and express his opinions.

- Adult learners are influenced by their own life experience. Experience and interests of adults should be used in developing materials and activities; this approach brings relevance and interest to the learning situation. Adult learners, when encouraged to contribute to the learning situation, value it and become invested in successful outcomes.

- In adults readiness to learn is based on the need to know, and is either problem-centered or grows out of a personal need for self improvement.

While some adult learners are "thinkers" and "reasoners" and will be independent learners, others approach learning from a more pragmatic viewpoint and best learn in their own environment with hands-on experience. Some adults are more realistic in their learning style and just want to know "how to do it"; they may not be interested in the human relations aspects of learning. Still others believe that there is no right way and are willing to consider various approaches. Few adults fall exclusively into one category but may show greater strength in one category than in others. Individual adults may learn best through visual, auditory, or tactile-kinesthetic modalities.

Consideration given as to how an individual best learns can assist you not only in information sharing but also in building a positive relationship (Sakata, 1984).

**Strategy 12: Program activities are implemented in ways that promote the development of self-esteem, social skills, internal control, social role comprehension, & problem-solving.** At the core of empowerment is the principle of creating opportunities in early intervention for parents to exert control over their own lives and those of their children. Elsewhere we have talked about the relationship between empowerment for parents with special needs/mental retardation and five behavioral areas related to their life experience. Effective early intervention, then, creates opportunities for parents to participate in meaningful social interactions, to make choices, and to learn from the consequences of those choices. Traditionally, early intervention programs frequently have been controlled by professionals from the point of referral, to the structured activities within any given day, to the decisions made regarding transition. Instead, professionals should assess their method of service delivery to revise it in ways that consider and promote

- self-esteem and self-worth by valuing the parents' perspective;
- opportunity for social skill development by providing/modeling social skills opportunities;
- internal control by putting the parent in charge;
- understanding of what it means to be a parent by modeling and experience;
- development of problem-solving skills.

Some parents with special needs/mental retardation may at first have difficulty in becoming "empowered," for such experiences typically have not been available to them. For these families, it may be helpful to provide initial opportunities for simple, concrete decisions: for example, if a program has a snack time, parents could be asked, "Would your baby like a banana or a cracker?", rather than program staff deciding on behalf of the child. Similarly, if the parent has identified making toys as a goal, the parent could be asked to choose which one of two or three she thinks her baby would like best. Even "therapeutic" goals can be presented in ways that allow decision-making; several activities or exercises could be presented, with the parent given the opportunity to choose which one (or none) she would like to learn. As parents gain confidence in their decision-making, they are likely to participate in increasingly active ways. For example, after eight months in the program, one mother proudly told another "You should have been here last week. We came up with things to do for the whole year!"

**Strategy 13: Program utilizes techniques that facilitate effective learning environments in which parents with special needs/mental retardation can become more competent.** Use total communication, words movements, prompts, and touch. Check often to be sure you are understanding each other.

We often unwittingly make assumptions about parents' ability to understand. While professional consciousness may have been raised around issues of the difficulty that non-professionals have in understanding acronyms and professional terminology, typically the spoken word is heavily depended upon in communicating information to parents. Both the parents with special needs/mental retardation and the professionals working with them can benefit from using fewer words and more action. Human touch is a valuable communication tool that is not often used when working with adults. Touching a person's arm or shoulder when speaking to them or guiding their hand when appropriate to demonstrate a task can be a powerful assist to supporting the parent and modeling an approach. Modeling a behavior or demonstrating information to be imparted is another effective communication tool, especially if the modeling style is a comfortable match to the parents. Checking to ascertain whether or not you and the parents are understanding one another is a delicate ongoing process. Invitations to help the parent might be phrased, "Let me help you try it", invitations to participate with you might be phrased, "Let's do this together." Blunt yes or no questions such as "do you understand?" should be avoided. Astute observation during interaction can provide valuable insight into the level of parental understanding.

Use involvement in a task as a vehicle to assist a parent in controlling a situation. Involvement in accomplishing a task is a helpful refocusing tool when you sense that the parent is either close to being out of control of a situation or feeling left out and intimidated. Inviting the parent to help accomplish a task with you or another parent can remove the focus from the uncomfortable situation at hand, while allowing the door to remain open for positive interaction.

Sharing a task and modeling are more effective techniques than directing or telling. Explaining and showing while sharing a task is more effective than simply verbally telling how to do something. Similarly, explaining or showing something in a positive manner is more effective than explaining what one is not to do. Accentuate the positive; minimize the negative. "Don't do that" and "don't do it that way" are two phrases to be avoided. If a behavior is to change or improve, a replacement must be found. To say to a parent "your baby shouldn't eat that; he may choke" is certainly important information, but to add "this would be safer" and offer a concrete example with a discussion of "why" provides an ideal opportunity for modeling through the sharing of life experiences.

Sharing life experiences is a valuable tool which can be used to break down barriers between parents and professionals. Looking for commonalities between experiences of the parent and ourselves can assist us in understanding one another. The mother who has just experienced a temper tantrum by her two year old in the grocery store can be quite encouraged to know that the "professional early intervention specialist" with a two year old has experienced the same embarrassment. Consequently, the pertinent issue of how to handle the behavior can then be readily discussed. A "willingness to share" shows parents an openness and acceptance that may be unfamiliar to them and reveals the interventionist as "someone else" who experiences real child care issues in her own family.

Anticipate, and in doing so, help avoid unpleasant or destructive interactions. If you know a parent has a low tolerance for certain situations or people, plan alternatives that will be more acceptable. Similarly, if difficult information needs to be discussed with the parent and you have some prior experience that gives you clues as to how the parent may react, be prepared with some alternative approaches so that your relationship is maintained and communication will remain open.

Mistakes are okay - for everybody. It is extremely difficult, if not impossible, to consistently deliver service that recognizes every parent's individual strengths and needs. Mistakes in observation and judgment will and do occur both on the part of the parent and the professional. Parents are generally surprised and pleased when a professional can admit, "I didn't understand," or "I made a mistake, " and will be much more likely to make such an admission themselves. In one program, the success of this approach was illustrated by a mother who had experienced the kind of acceptance that admitting mistakes allows, who said to a new mother, "You'll like it here--they don't make you feel stupid."

**Strategy 14: Program staff utilizes strategies for effective help-giving.** Key principles for help-giving that can effectively empower families have been identified by Dunst, Trivette and Deal (1988, p. 97):

- Be both positive and proactive in interactions with families.
- Offer help in response to family-identified needs.
- Permit the family to decide whether to accept or reject help.
- Offer help that is normative.
- Offer help that is congruent with the family's appraisal of its needs.
- Promote acceptance of help by keeping the response costs low.
- Permit help to be reciprocated.
- Promote the family's immediate success in mobilizing resources.
- Promote the use of informal support as the principle way of meeting needs.
- Promote a sense of cooperation and joint responsibility for meeting family needs.
- Promote the family members' acquisition of effective behavior for meeting needs.
- Promote the family members' ability to see themselves as an active agent responsible for behavior change.

These principles are especially important for parents with special needs/mental retardation, for their array of needs and behaviors may evoke an initial paternalistic response in service providers. However, the use of these principles provides the opportunity for parents to make gains in the five behavioral areas described in Chapter Two. Several of these principles should be given special emphasis when working with parents with special needs/mental retardation.

∗Permitting a family to accept or reject help can be painful whenever we perceive parents with special needs/mental retardation to have many needs; however, to provide that opportunity for decision-making is important for self-esteem, internal control, and problem-solving.

∗Offering help that is normative (e.g., not rushing out to buy a new kitchen table and chairs) may require professionals' being sensitive to their own values and expectations; offering help that we think is normative may perpetuate the stereotype that persons with special needs/mental retardation are inferior.

∗Permitting help to be reciprocated provides valuable opportunities for self-esteem, social interaction, problem solving, and ultimately partnership-building. For example, a mother in your program brings in a sackful of worn, but clean baby clothes for a pregnant staff member. The staff member may respond uncomfortably that she already has enough clothes for the expected baby... or, she could graciously accept the gift and view the mother's action as an example of appropriate social interaction and problem solving.

∗Promoting immediate success requires a realistic evaluation of our expectations as well as the parent's existing strengths in the five areas described in Chapter Two. If we inadvertently create a situation where parents cannot possibly succeed, then the "fault" lies with us, not the parent. For example, if a parent cannot read, communicating appointments by mail may prevent the parent from keeping the appointment and ultimately may result in the parent's being labeled "resistant."

∗Promoting the use of informal support may be difficult for two reasons. First, our initial response to persons with a variety of needs is to link them with an array of agencies; secondly, societal attitudes toward adults with special needs/mental retardation may hamper their participation in informal support systems. Although many parents with special needs/mental retardation may need some kind of professional involvement until their children are grown, the wider their informal network, the more likely they are to be able to meet the ever-changing needs of their children.

∗Promoting acceptance of help by keeping the response costs low is of primary importance to many families in which parents have special needs/mental retardation due to their low socioeconomic standing. It has only been in recent years that employment at competitive wage has become a realistic option for adults with special needs/mental retardation. Therefore, the families you are striving to serve may be less responsive to and may actually reject expensive store-bought toys/equipment introduced in early intervention programs. Simple items that can be made are more likely to meet with success. The low response cost principle also applies when addressing such issues as family's transportation to a program and nutritional recommendations for the family. This principle also refers to the psychological cost of accepting help; assistance should be offered in ways that do not dearly cost the parent self-esteem and control.

**Strategy 15: Program has acquired sufficient curricula and resource materials to be able to respond to topics identified by parents with special needs/mental retardation.** Chapter Five presents various curricula and resources that are available, together with guidelines for evaluating their potential usefulness. However, because no one curriculum magically fits all families, success in the use of such resources and strategies depends strongly on the relationship established between parent and professional. If program personnel intend to provide families with appropriate services, as determined by each family's priorities and unique functioning, then intervention must be tailor-made to each parent with special needs/mental retardation. A series of sessions on topics identified only by professionals without family input is not consistent with the key principles of enabling and empowering.

Early intervention programs may unintentionally identify for parents "functional skills" and teach a series of responses; what emerges is a passive parent who continues to wait for an external cue. It is very important to provide opportunities for these parents to learn skills such as diapering, bathing, making formula, and promoting their child's development; however, it is helpful to provide such experiences in ways that not only are more "generalizable," but also promote self-esteem, internal control, and competence and, in addition, are offered at times when the need to acquire the information has been identified by the parent.

**Objective III: Growth in the family/community relationship:** To build a collaborative network of formal and informal support, in the realization that no one person/agency/organization is able to meet multiple, long-term needs of a family.

**Principle Four: The staff should enhance the collaboration between the family and a) multi-agency supports, and b) informal community supports.** In the follow-up of families participating in the PING program, the commonalities that emerged among the families who have remained together are consistent with the literature citing social support as a significant protective factor. These families had several key figures (both family members and professionals) who believed in their ability and who provided opportunities for competence to emerge. Those families whose children were removed permanently were characterized by a limited social system, the loss of a key support figure at a crucial time, or the continued view of them by key figures as incompetent.

**Strategy 16: Interagency collaboration must occur among multiple agencies.** Since many families in which parents have special needs/mental retardation are involved with multiple agencies, the ultimate success of the family may depend on agencies collaborating to define roles and responsibilities and deliver services. Any parent with a child at risk is involved with multiple services. Add to that the effects of poverty, limited social skills, and limited understanding and it is easy to see why parents with special needs/mental retardation do not fare well. A parent cannot understand how to traverse social, medical and other necessary community services without a commitment on the part of service providers to move from a cafeteria style of service, "This is what we have, take what you want," to a customized service, "We will assist you in identifying and acquiring what you want."

For effective interagency collaboration to occur, working agreements between services are needed and staff must establish interpersonal relationships with key service providers. Program staff need to know those community service providers who can get the problem solved within a reasonable period of time. These are contacts who know how to resolve the immediate issues between agencies, who know the appropriate services to benefit the family, and who can identify issues that need to be dealt with at a systems level.

For example, one mother with special needs/mental retardation and her three children, 6 months, 2 ½ years, and 5 years, all with special needs, were each receiving services from a different service provider, with unique and differing expectations for the mother. One professional wanted the mother to focus on feeding techniques for her oldest child who had cerebral palsy; another wanted the mother to toilet train her middle child in preparation for preschool; another service provider was teaching the mother exercises to improve the baby's hypotonia, while the mother's own case manager wanted her to focus on personal appearance and vocational opportunities. It came as no surprise, when the various agency representatives came together, that one professional commented: "Now I know why, whenever I drive up, it seems as though the mother spots me and says, "Oh, here's Rachel, I've got to start doing those baby exercises!" It also came as no surprise that all of the professionals had felt frustrated by the family's lack of progress. Even though each had established a strong relationship with the mother, they realized that their various expectations were overwhelming for the mother; their solution was to have one person meet with the mother and help her identify what one area she wanted to focus on in the next two or three months. While in this case the mother was receiving a great deal of social service support, lack of interagency collaboration was resulting in confusion and failure for both the mother and the service providers.

**Strategy 17: The family's informal support system of extended family and community friends should be identified and expanded.** Extended family and community friends often offer more appropriate, normative and more readily accessible support than the formal supports found in professional agencies. Building a strong relationship with a family, beginning with the initial IFSP, will enable staff to help a family identify both present and future sources of informal support. Research has consistently found that the success of "high-risk" families depends on the extent and stability of a support system that is easily accessed by families.

**Strategy 18: Transition for the child and family from program to program is carefully planned and executed.** Many parents with special needs/mental retardation may require some degree of ongoing formal supports; consequently frequent transitions are a reality for these families. Transition is most likely to be effective when

- the new agency or program has been carefully chosen in response to the needs identified by the family;

- the family has the opportunity to begin building a relationship with one person in the new agency before transition occurs;
- some overlap occurs between attending the old and attending the new program; and
- periodic follow-up occurs to ensure that the family has moved successfully into a partnership with the new program.

If at all possible, families should not be asked to move from a supportive program until an appropriate transition has been accomplished--even if the child or family no longer "qualifies" for that program. Furthermore, families should be encouraged to return to visit or contact the staff with concerns even after leaving a program. If internal control and problem-solving skills have been encouraged, then parents with special needs/mental retardation will not remain "dependent" upon us. All families, even parents with special needs/mental retardation, should be given credit for knowing when it is "time to move on."

**Strategy 19: The Individualized Family Service Plan is used as a vehicle for relationship building, empowerment and interagency collaboration.** The development and implementation of the Individualized Family Service Plan create countless opportunities to establish a trusting partnership with parents with special need/mental retardation. The IFSP is most productively viewed as process rather than product, as part of the journey together toward empowerment. The philosophical assumptions regarding the IFSP adopted by the Ohio Interagency Early Intervention Council are explored in Figure 2 on page 38 with regard to parents with special need/mental retardation.

**Figure 2:** The philosophical assumptions regarding the Individualized Family Service Plan adopted by the Ohio Interagency Early Intervention Council are explored with regard to parents with special needs/mental retardation.

| | IFSP Assumptions | | Parents with Special Needs/Mental Retardation (According to Ohio Interagency Early Intervention Council, 1990) |
|---|---|---|---|
| 1. | Families are basically competent individuals as well as competent caregivers. | 1. | The literature and experiences show that parents with special needs/mental retardation can learn to be capable caregivers. |
| 2. | Families and interventionists are important sources of information regarding the young child with special needs. | 2. | Parents with special needs/mental retardation can also be important sources of information once a relationship of mutual respect and trust has been established. Typical approaches to elicit information may not be appropriate. |
| 3. | IFSP's should be future-oriented; current goals and objectives should reflect movement toward the next environment. | 3. | Transition must build upon the strengths of parents with special needs/mental retardation in order to insure successful movement for the child; success is related to opportunities for increased problem-solving and self-assessment of family needs. It must be recognized that many families may need to access a long-term support system. |
| 4. | Needs (for support, educational programs, related services) identified by families should be addressed via the IFSP. | 4. | The priorities of parents with special needs/mental retardation will dictate development and successful implementation of the IFSP. Such needs may include housing, day care, and vocational desires. |
| 5. | IFSP goals should allow for other family interests and activities and avoid total investment of the family in the child's intervention. | 5. | IFSP goals should reflect the reality that parents with special needs/mental retardation are more likely to be involved with their children when their own needs are also being addressed. |
| 6. | Service providers and/or interventionists are basically competent individuals and act in good faith while protecting the rights, privacy, and confidentiality of families. | 6. | Service providers and/or interventionists can assist parents with special needs/mental retardation by assessing their own attitudes and expanding their opportunities for "life-sharing." |
| 7. | Cultural/sub-cultural differences of families should be considered in assessment, service planning, and intervention. | 7. | Assessment, service planning, and intervention can be facilitated through understanding behaviors and learning styles of parents with special needs/mental retardation. |
| 8. | The IFSP document, service coordination, and planning process will reflect a collaborative effort of parents and interventionists; an advocate of parent's choice may also be included in the planning process. | 8. | The development of the IFSP, service coordination, and planning process may be facilitated by including someone who has an established, positive relationship with the parent with special needs/mental retardation. |
| 9. | The IFSP is a functional child and family centered document based largely on the interests of the family; the "ownership" of the plan rests with the family, not a particular agency or service provider. The IFSP will include specific goals and objectives to be carried out by each interventionist. | 9. | In order for the IFSP to be a functional child and family centered document for parents with special needs/mental retardation, it is even more critical to view it as a flexible, every-changing, process-oriented document in which specific goals and objectives need to be addressed collaboratively. Opportunities for parents to experience "success" can be carefully developed through the IFSP process. |
| 10. | Families have a right to choice in services; the service system must acknowledge the variability of family functioning and the ways in which families pursue their priority goals. | 10. | Parents with special needs/mental retardation have a right to make choices...to succeed...and to fail. The service system must acknowledge realistic expectations for parents with special needs/mental retardation. |
| 11. | The IFSP and service coordination processes should allow for a continuum of family involvement. | 11. | Early intervention can enable parents to understand that their experiences with professionals can be rewarding rather than punitive. The IFSP and service coordination processes should be a route to empowerment and increased independence for parents with special needs/mental retardation. |
| 12. | Families can initiate change within the IFSP process according to their needs, i.e., initiate planning, enter or exit the service systems, change type or level of services. | 12. | So that parents with special needs/mental retardation can initiate change within the IFSP process, service providers will want to be sensitive to changing family needs and strategies for effective help-giving. |

(According to Project CAPABLE, 1990)

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# STRATEGIES FOR PROVIDING OPPORTUNITIES FOR PARENTS WITH SPECIAL NEEDS/MENTAL RETARDATION

Understanding how the life experiences of adults with special needs/mental retardation can affect their behaviors as parents is the first step in what Turnbull and Turnbull (1986) describe as "empathetic reciprocity" ... "to put ourselves in the place of others as fully as we can, looking at the world from their perspectives and using their values and needs" (p. 106). This crucial understanding paves the way for building a parent professional relationship in which opportunities are created for parents to grow in the five key areas: self-esteem, social interaction, internal locus of control, social role comprehension, and problem-solving.

The following strategies for providing those opportunities for parents with special needs/mental retardation have been identified not only by the past and present staff of UACCDD's early intervention program, but also by a network of resource teams trained by Project CAPABLE throughout the state of Ohio. These teams are comprised of persons from a variety of settings and systems (early intervention, adult services, health, social services, public schools, and parent advocacy groups) who represent the collaborative network of support so important for the "success" of parents with special needs/mental retardation.

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# SELF-ESTEEM

**Self-esteem:**

A positive or negative attitude of one's self, which can fluctuate in different situation

**Observable behaviors that indicate parent need:**

✓Parent displays little or no eye contact
✓Parent takes little pride in physical appearance
✓"I can't do that."
✓Parent displays nonverbal behavior: nervous mannerisms, arms folded tightly against chest
✓Parent isolates self in group
✓Parent refuses to voice opinion
✓Parent is overly compliant

**Strategies:**

- Welcome parents: "Hi,_ _! It's good to see you again."
- Share sincere compliments.
- Identify and build upon parent's strengths: e. g. , arts & crafts, preparing snacks, music, reading to child.
- Involve parents in program: e.g., planning activities, coordinating snack, welcoming new parents.
- Invite parent to share successes with other parents and staff.
- Use a gentle sense of humor to develop rapport: above all, be able to laugh at yourself.
- Set realistic goals at which parent is likely to succeed.
- Follow through with what you have promised to do in order to build trust.

# SOCIAL INTERACTION

| **Social interaction:** | **Observable behaviors that indicate parent need:** |
|---|---|
| The extent to which a caregiver becomes actively involved in interactions with peers and staff | ✓Parent isolates self<br>✓Parent nods or shakes head; minimal verbal response<br>✓Parent does not initiate conversation<br>✓Parent monopolizes conversation<br>✓Parent makes fun of others |

**Strategies:**

- Recognize and relate to parent as peer.
- Ask parent for opinions and use active listening to feed back what you have heard.
- Look parent in eye when speaking.
- Don't jump in before parent has had a chance to respond to what you've said.
- Don't just repeat what you've said when parent doesn't seem to understand. What you need to do is clarify.
- Manipulate physical environment to draw parents more closely together. Sit close to parents. Encourage them to sit closely to one another.
- Use a concrete task (e.g., making toys, cooking) to provide a comfortable vehicle that facilitates social interaction.
- Draw parents into conversation with other parents: "Mary, you've talked about this before. What would you suggest."
- Be ready to redirect potentially hurtful remarks.
- Provide opportunities for parents to interact without professionals being present.
- Provide opportunities that promote community integration: obtaining library cards, visiting local parks, going to the zoo.
- Provide social opportunities that parents may have missed: e.g., celebrate birthdays of parents as well as of children.
- When appropriate, use touch to demonstrate the positive value of human interaction.

## LOCUS OF CONTROL

**Locus of control:**

The perception of events actions that influence one's life as either the consequences of one's actions (internal) or as the result of outside forces (external)

**Observable behaviors that indicate parent need:**

✓Parent is passive and or withdrawn
✓Parent blames others
✓"Whatever you say, I'll Do" (but doesn't); "You decide. I can't."
✓Parent tries to get the professional to provide "excuse" to justify the parent's behavior

**Strategies:**

- Allow parent to participate in decision-making: for some parents, it will be necessary to begin with "small" decisions, e.g., "Does your baby want bananas or peaches for snack today?"
- "I don't know the answer to that. What do you think, Mary?"
- "I can't make that decision for you. I'm here to support whatever you choose. Let's sit down and talk about this."
- Make sure that the parent can experience success in the choices that are provided.
- Use effective help-giving strategies (Dunst, Trivette, & Deal, 1988, pp. 94-96) to place locus of control within family.
- Monitor your own verbal and nonverbal behaviors. Are you in control or sharing control with the parent?
- Plan with the parent in assuming control of situations outside your relationship: e.g., together prepare a list of questions for the pediatrician.
- Support the parent's attempts to assume internal control by providing ongoing support; e.g., initially accompany the parent to the doctor's appointment.

## SOCIAL ROLE COMPREHENSION

**Social role comprehension:**

A caregiver's understanding of and fulfillment of the multiple roles one has in the family and in society

**Observable behaviors that indicate parent need:**

✓Parent places own needs before those of child
✓Parent attributes adult motives to child's behavior
✓Parent does not interact with the child in front of you (perhaps for the fear of failing)
✓Parent does not know how to "play" with child
✓Parent demonstrates little knowledge of basic child care
✓Parent is either overly punitive or afraid to discipline child

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**Strategies:**

- Take time to identify what the parent already knows about parenting: make no assumptions and take nothing for granted about the parent's level of understanding.
- Explore how the parent herself was parented: link the parent's feelings, both positive and negative, to how her parenting will impact her child.
- Focus on helping the parent read and respond to the child's cues here and now.
- Opportunities to learn about child development should be tied concretely to the child's present developmental level.
- "Anticipatory guidance" is helpful only when linked directly to what the parent presently understands.
- Present information in a way that respects the cultural/socioeconomic setting of the family.
- Some "rules" are necessary, e.g. , "Never hit your child;" however, most information should be presented in a format that promotes generalization and problem-solving rather than memorizing absolute rules.
- Your relationship with the parent is the most effective curriculum tool available to you: "life-sharing" about being a parent is perhaps the most powerful way to convey information that the parent can and will incorporate.
- Examine your expectations for the parent: how "realistic" are you? No two parents make identical decisions or establish identical priorities.
- None of us know all there is to know about parenting. A characteristic that may distinguish the parent with special needs/mental retardation from other parents is a reluctance to ask for assistance from others. Create an atmosphere in which everyone, parents and professionals, freely ask questions and admit, "I don't know."

## PROBLEM-SOLVING

| **Problem-solving:** | **Observable behaviors that indicate parent need:** |
|---|---|
| The ability to seek solutions to address an issue effectively | ✓Parent chooses same option repeatedly despite lack of success<br>✓Parent depends on others to solve problems<br>✓Parent procrastinates |

**Strategies:**

- Identify and refer back to situations in which the parent has been successful in solving a problem: help the parent identify what worked.
- Provide workable choices that maximize success and minimize failure.
- Help the parents to generate options and explore the consequences of those options.
- Use "life-sharing" to identify some additional options available to parent.
- Clarify that the parent has the available skills and supports necessary to implement the option chosen.
- If necessary, assist the parent through the initial steps of implementing the choice; gradually decrease the amount of assistance you provide.
- Role playing and rehearsal can help parents practice options they previously would not have considered.
- Parents often are more likely to consider solutions proposed by other parents rather than by professionals.
- Once a decision has been made, be available to support the parent, **even though you may disagree with that decision.**
- Celebrate risk-taking: as much can be learned from failure as from success.

# CHAPTER FOUR
# EVALUATING PROGRESS

Professionals working with parents with special needs/mental retardation may perceive the process of change to be both slow and seemingly minute. Given the fact that traditional methods of measuring change (e.g., paper and pencil tests, detailed observational measures) may not be optimal for families or for service providers, it is crucial to view change in alternative, even unlikely ways. For example, attendance records can provide insight into a family's perception of the value of the program to them. Excellent program attendance by a family previously viewed by multiple agencies as an uncooperative "no show" is evidence of progress. Just as it is imperative for program philosophy to be linked directly to program implementation, so should program philosophy be tied to strategies for evaluating change.

Table 1, found on page 50, explores some key questions, strategies, and tools for collecting data on change. We are not suggesting these as a comprehensive system for evaluating all aspects of an early intervention program, but rather as additional strategies to address ways of measuring the success of parents with special needs/mental retardation.

**The Individualized Family Service Plan.** The development, implementation and reviews of the Individualized Family Service Plan (IFSP) provide many opportunities for evaluating change. If the IFSP is to be used as an effective tool to examine progress made by parents with special needs/mental retardation, then it is imperative to consider four questions raised by Bailey, Winton, Rouse, and Turnbull (1990):

1. What is the nature of family goals? Must family goals be included in the IFSP for early intervention to be truly family focused?
2. How should meaningful and useful statements regarding family strengths be incorporated into the IFSP?
3. To what extent should family goals contain specific statements about the conditions and criteria for goal attainment?
4. How important is it for the IFSP to include "higher-level" family goals?

## Table 1: Questions, Strategies and Tools for Evaluating Change

| Objective | Questions | Strategies | Tools |
|---|---|---|---|
| Family-staff relationship | Can we demonstrate that a trusting relationship has been established with each family? | Collect data on program attendance | Attendance record |
| | | Document needs outcomes, strengths and strategies as identified by parent | IFSP development |
| | | Document assistance/support provided by program staff and family | Records on individual child |
| | | Document staff planning session | Minutes from meeting |
| | | Document consumer satisfaction | Interview to complete program's consumer satisfaction form |
| Family-child relationship | Can we demonstrate that parents have made gains in the areas of self-esteem, skills, role comprehension, and problem-solving? | Record observations of parents in five areas | *Daily Record Keeping Form |
| | | Collect data from other agencies involved with family | *Daily Record Keeping Form |
| | | Periodically review to determine if gains are being made | *Parental Behavior Profile |
| | | Document progress toward achieving jointly identified outcomes | IFSP reviews |
| Family-community relationship | Can we demonstrate that we have assisted families to expand their network of formal and informal supports? | Document changes in support network | Inventory of Social Support (Trivette, & Dunst, 1988) |
| | | Document interagency collaboration on behalf of family | IFSP |
| | | Document contacts with other agencies | Records on individual child and family |
| | | Collect follow-up data after family has left program | IFSP (transition)<br>Follow-up records |

*Tools being piloted and revises through Project CAPABLE, 1988-1991.

Family Goals: Many parents with special needs/mental retardation may be unable to meet the needs of their children unless their own needs are addressed first; consequently, IFSP's for these families are likely to contain multiple family goals, some of which center on the child and some of which focus on the parent. Examples of the former would include "Nancy would like some suggestions for potty training so that she won't have to buy diapers and so that Melissa will be more independent" or "Rebecca and Joe will take Danny on walks and talk to him about what he is seeing so that Danny will say more words." Examples of parent-centered goals which nevertheless have direct impact on the child's well-being include "Sue would like to learn to read so that she can keep track of Eric's appointments" and "Lois would like to move to a different apartment so that she can have a safer home for Tom." Clearly these last two outcomes raise a major concern common to early intervention professionals: should we create opportunities for families to talk about needs that cannot be addressed by our program? From the CAPABLE perspective the response is "yes," for such issues can have critical impact on the development of the child. The logical conclusion is not that one program must meet all needs of parents with special needs/mental retardation, but that programs must be willing to collaborate, often with adult service agencies, on behalf of the family. For example, a mother wanting to learn to read could be linked to an adult literacy program or a vocational program, while a mother seeking a new apartment might be assisted by a local housing agency (public or private) or a caseworker/case manager from an adult services system.

Family Strengths: Bailey, Winton, Rouse, and Turnbull (1990) note the tendency to describe family strengths in brief global statements that are not directly linked to outcome. Since parents with special needs/mental retardation often present situations in which "strengths" are not readily apparent, we have found it most useful to link strengths directly to each outcome.

**For example:**

Desired Outcome: Nancy would like some suggestions for potty training so that she won't have to buy diapers and so that Melissa will be more independent.
Identified by: Nancy

Family strengths, needs, and resources for this outcome: a) Parents at home with Melissa; b) Parents have toilet trained three older sisters; c) Parents need timer to remind when to go potty; and d) Family already has potty chair at home.

**... or**

Desired Outcome: Sue would like to learn to read so that she can keep track of Eric's appointments.
Identified by: Sue

Family strengths, needs and resources for this outcome: a) Sue is very interested in learning how to read; and b) Sue lives in a housing complex where an adult literacy program meets.

Specificity of Outcomes: When working with parents with special needs/mental retardation, who rarely have been viewed as successful," it is helpful to identify clear, specific outcomes since "progress" often is slow and occurs in small steps; consequently, keeping in focus the ultimate goal allows professionals and parents to "stay on track" and to break down the outcome into steps easily achieved by both parents and professionals. A key strategy is to include in the outcome statement a phrase beginning "so that." For example, "learning to read" and "finding a new apartment" are open-ended goals that contain no clear descriptions of "success." However, Sue would like to read well enough so that she can keep track of appointments mailed to her; Lois will have achieved her outcome when she has moved to an apartment that does not contain safety hazards placing her baby at risk.

"Higher-Level" Goals: Bailey, Winton, Rouse, and Turnbull (1990) point out the connection between more complex goals and family empowerment and independence. For parents with special needs/mental retardation, this is a crucial issue to consider, for their ultimate success in parenting literally depends on opportunities to develop higher-level skills in the five areas noted throughout this handbook. "Finding an apartment" can be an incredibly complex task which requires the opportunity to develop and integrate such knowledge and skills as:

- Reading the want ads in the newspaper
- Understanding the location of available apartments within the city/community
- Dialing the telephone
- Asking the proper questions during a telephone contact
- Understanding how to budget so that a reasonable amount for rent can be estimated
- Knowing how to fill out application forms
- Having transportation available to check out prospective housing.

Consequently, a program's commitment to developing higher level goals with families also must contain a commitment to breaking goals down into realistic steps and collaborating with other agencies and systems to ensure that parents can achieve each step in the process.

Once the family's goals have been established through the IFSP, ongoing observations can be recorded through the use of the Daily Record Keeping Form with Behavioral Descriptors. The observations are then accumulated quarterly into a summation on the Parental Behavior Profile. Use of the IFSP and the Parental Behavior Profile allows flexible ongoing assessment, as well as a quarterly overview of the cumulative effects of the intervention. The program is able to assess not only the family's and child's progress towards goals, but also the staff/program effectiveness in helping the family achieve goals. This type of qualitative evaluation can document change in the family's service needs and can address the community collaborative effect (other agencies involved with each family).

Both the Daily Record Keeping Form with Behavioral Descriptors and the Parental Behavior Profile were developed by combining optimal behaviors for all parents as found in a review of the literature together with those that have been found to be particularly important for parents with special needs/mental retardation. These concepts were then expanded by adding behavioral examples from the extensive clinical notes kept by the PING staff.

**The Daily Record Keeping Form with Behavioral Descriptors.** Instead of keeping progress notes concentrating solely on the child, we suggest that programs keep notes on parental behavior with additional references to the child's progress. The Daily Record Keeping Form provides the opportunity to record behaviors in the five key areas: self esteem, social skills, internal control, social role comprehension, and problem-solving skills. An extensive list of behavioral examples accompanies the form to assist staff in identifying behaviors they are observing.

The labor intensive process of recording behaviors after each session on the Daily Record Keeping Form pays off when staff rereads their notes and can see changes in behavior. Because staff time in parent groups may be required to assist parents to work through crisis situations, it is sometimes difficult to see that, in spite of intervening circumstances, parents are becoming more successful. Figure 1 seen on page 54 contains an example of notes kept on a family in the area of social role comprehension.

In addition, whenever possible, we would suggest the use of videotaping. This is an excellent way to actually see changes in parental behavior over a period of many weeks and can enhance the staff's ability to observe change. Videotape also assists the professional staff to analyze their interactions with the parents to determine the effectiveness of their approaches in achieving desired outcomes.

**Figure 1: Example of Daily Record-Keeping Form (Social Role Comprehension) Completed by PING Staff on Family A**

4. Social Role Comprehension
Data/observations that document progress:

R has made playroom for kids & placed their toys there: said E & D will play for long periods of time unless hungry or wet. R jumped up for baby when she lost her balance: said she is afraid D will hurt herself. R described D's progress in last couple of weeks: is excited she is more mobile & pulling to stand. R concerned over lack of baby gate in new apartment. When questioned on next IFU clinic appt., R said had lost phone # and asked us to get it for her again: said would call immediately upon arrival at home so D could get appt. R still concerned that WIC say D is underweight-wants IFU to reassure WIC re: growth curve. R says she has to "make time" now to give E special attn. Because D is so vocal & demanding of attn. R does not want E to feel out. R says E is now requesting specific foods: much more verbal. We discussed E's progress since returned home (possibly linked to R's full attention & stability of routine.) R concerned that D would accidently harm another baby in group. Asked trainee to watch her closely because baby winced when D crawled upon his leg.

Barriers/circumstances that have hindered progress:

Follow-up:

4-17-90 will research availability of baby gate

4-26-90 ME-S will bring baby gate from home

**The Parental Behavior Profile.** The selected behaviors of self-esteem, social skills, internal control, social role comprehension, and problem solving significantly impact parenting skills. These five behavioral components reflect areas in which adults with special needs/mental retardation need to develop strengths if they are to be competent parents. The Parental Behavior Profile was developed to review and summarize historical information from the Daily Record Keeping Form and to assist staff in recognizing progress made by families.

Use of the Parental Behavior Profile can assist staff in looking objectively at parent behavior to see the positive changes that have occurred. One or more staff members can complete these initial observations within two weeks of a family's entry into the program. An assessment of parent growth utilizing the Parent Behavior Profile should occur every three to four months and be reflective of behaviors observed and recorded on the Daily Record Keeping Form. The profile can be compiled by various program staff as a means of promoting discussion; it can also be completed by raters within various service systems working with a family to see if their independent observations coincide. The intent of the Parental Behavior Profile is not to rate parental "competence" or compare families, but rather to provide programs with a strategy for documenting progress. Figure 2 seen on page 56 contains an example of two staff members on two different occasions completing the profile on a mother in the area of social role comprehension.

Both the Parental Behavior Profile and the Daily Record Keeping Form support family-focused intervention by encouraging interaction among parent(s), child(ren) and staff. By focusing staff's attention on specific behaviors, daily record keeping and periodic review become ways to closely monitor changes in parental behavior and growth toward the overall program objectives. This information assists the staff in building their relationships with parents and in working with the parents on those strengths necessary for competent parenting. As parents gain confidence in themselves and in the professionals with whom they are working, changes are more readily seen in the five behavioral areas. Growth in these five areas reveals parents who are better able to interact with their child, the staff, and the community.

Both the Daily Record Keeping Form and the Parental Behavioral Profile are in the process of revision. If your program wishes to participate in the revision process by utilizing either of these tools, please contact Marilyn Espe-Sherwindt at (330) 633-2055 or write to the Family Child Learning Center, 143 Northwest Avenue, Bldg. A, Tallmadge, Ohio 44278.

**Figure 2:** **Example of Parental Behavior Profile Social Role Comprehension Completed by PING Staff on Family B**

Name of Caregiver/Parent C Name of Child R DOB 1-22-89

IV. Behavioral area: Social Role Comprehension (circle one number)
a caregiver's understanding of and fulfillment of the multiple roles one has in the family and in society

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| looks at child | cares for child's physical needs | prompts child to play | praises child | shows interest in developmental milestones/issues |
| child has been removed from home | lets others care for child when unable to | protects self | talks to child | follows child's progress |
| discipline of child involves inappropriate physical force, even for cultural background | discipline of child with physical force only when necessary | protects child | imitates child's vocalizations | demonstrates concern for others' rights |
|  | discipline by yelling and abusive language | discusses role as parent | demonstrates interest in goals for self | "standing up" for one's own rights |
|  |  | discipline of child is appropriate to situation and is not physically or verbally abusive | helps others when possible |  |
|  |  |  | offers advice to other parents |  |

(Ed. Note: "K" and "L" denotes two different staff people)

Additional Notes:
- C has been gently questioning of other parents' methods (toilet-training, meals, etc.)
- C brings baby utensils and appropriate food for R to participate in snack time
- is attentive to R's physical needs
- praises R's developmental milestones in front of other parents
- discipline of D has improved, though continued follow-up would be indicated

## CHAPTER FOUR REFERENCES

Bailey, D. B., Winton, P. J., Rouse, L. & Turnbull, A. P. (1990). Family goals in infant intervention: Analysis and issues. Journal of Early Intervention, 14(1).

Trivette, C. M. & Dunst, C. J. (1988). Inventory of Social Support. In C. J., Dunst, C. M. Trivette, & A.G. Deal. Enabling and empowering families: Principles and guidelines for practice (pp. 159-163). Cambridge, MA: Brookline Books.

# CHAPTER FIVE
# RESOURCES

I. Guide to Evaluation of Curricula

II. Audiovisual Materials

III. Manuals and Curricula

IV. Projects

V. Annotated Bibliography

## I. Guide to Evaluation of Curricula and Resource Materials for Parents with Special Needs/Mental Retardation

An effective early intervention program bases its activities, curricula and resources on the strengths and needs identified by the family. The following series of questions helps staff focus on the appropriateness and potential usefulness of these resources in contributing to the success of a program designed for families in which the parents have special needs/mental retardation.

✔ Did the family identify this topic as a priority need?

✔ Does the material need to be adapted or changed significantly to respond to the family's need?

✔ Is the level of information appropriate to the topic and to the family? Is reading required? At what level?

✔. Is the information consistent with the values of the family and their community?

✔. Does the material make use of principles of adult learning theory?

✔ Does the material provide opportunities for success in one or more of the five key behaviors (as defined by Project CAPABLE) that influence parenting?

✔ Are objectives clearly stated?

✔ Does the material invite interaction?

✔ How will you evaluate the effects of using this material?

CAPABLE 5/90

## II. Audiovisuals

Sixty Minutes. Donna & Ricardo's Baby (Video). (1990). (Available from 19 Gregory Drive, South Burlington, VT 05403) ($33.45)

> In this segment from 60 minutes Mike Wallace explores the issues involved when married adults with mental retardation have children.

Espe-Sherwindt, M. (Producer). (1986). Where he belongs-early intervention with high-risk families. (Video). Cincinnati, OH: University Affiliated Cincinnati Center for Developmental Disorders. (513) 559-4321.

> This videotape explores special considerations involved in providing early intervention services to the baby with developmental disabilities who has parents with special needs/mental retardation. It delves into the question of how our perceptions of these families affect the way we deliver early intervention services to them. Special techniques for effectively serving this population, which includes implications for professionals and the early intervention system, and ways of measuring effectiveness are also explored.

Espe-Sherwindt, M., & Kerlin, S.L. (Producers). (1989). I love somebody: Safety in the home (Video with discussion leader's manual). Cincinnati, OH: Project CAPABLE, University Affiliated Cincinnati Center for Developmental Disorders. (513) 559-4321. Purchase $30.

> I Love Somebody: Safety in the Home is a video (16:33) with Discussion Leaders' Manual designed as an aid to professionals in their work with parents who have special needs/mental retardation. The video presents three parents with special needs/mental retardation who show the viewer how to make a living room, a bedroom, a bathroom and a kitchen safer for their children. The video and Discussion Leader's Manual are designed to evoke discussion about dangers in the home and to increase knowledge of how to make a home safer for children age 0-2.

Espe-Sherwindt, M., & Kerlin, S.L. (Producers). (1990). I love somebody: Partnerships in parenting (Video). Cincinnati, OH: Project CAPABLE, University Affiliated Cincinnati Center for Developmental Disorders. (513) 559-4321. Purchase $25.

> I Love Somebody: Partnerships in Parenting is a video (6:00) that presents the concept that parents with special needs/mental retardation, their children and those who work with them benefit from the development of working partnerships that address family strengths and needs rather than only specific child issues.

Espe-Sherwindt, M., & Kerlin, S.L. (Producers). (1990). I love somebody: Feeding my baby (Video with discussion leader's manual). Cincinnati, OH: Project CAPABLE, University Affiliated Cincinnati Center for Developmental Disorders. (513) 559-4321. Purchase $30.

> This videotape and Discussion Leader's Manual provide opportunities for discussions with parents with special needs/mental retardation on a variety of issues related to feeding their young children (0-2).

Espe-Sherwindt, M., & Kerlin, S.L. (Producers). (Available 1991). I love somebody: Together we get along (Video with discussion leader's manual). Cincinnati, OH: Project CAPABLE, University Affiliated Cincinnati Center for Developmental Disorders. (513) 559-4321. Purchase $30.

> This videotape and Discussion Leader's Manual describe some common situations that can cause conflict between young children and their parents. Parents with special needs/mental retardation discuss ways to resolve those situations in positive ways.

Espe-Sherwindt, M., & Kerlin, S.L. (Producers). (Available 1991). I love somebody: Getting services for my baby and me (Video with discussion leader's manual). Cincinnati, OH: Project CAPABLE, University Affiliated Cincinnati Center for Developmental Disorders. (513) 559-4321. Purchase $30.

> This videotape and Discussion Leader's Manual explore strategies for self-advocacy and empowerment for parents with special needs/mental retardation and their young children.

University of California - Extensive Media Center. This child is mine (Video). (Available from 2176 Shattuck Ave. Berkeley, CA 94704. (415) 642-0460). $195 purchase, $40 rental.

> This video (29:00) focuses on four women with developmental disabilities and their ability to be good mothers with the help of supportive services.

## III. Manuals and Curricula

Cordes, M., Lee, M., & Reeves, M. Getting along with your child. (Available from Defiance County Board of MR/DD: 195 Island Parkway, Defiance, Ohio 43512.)

> This manual was designed to help parents with mental retardation develop daily routines to avoid conflicts. The manual consists of illustrative photographs in the following areas: 1) Infants 6 to 12 months - Safe toys and safe places to play; 2) Toddlers 12 to 24 months - Eating and bedtime; 3) Toddlers 24 to 36 months - Dressing, picking up toys, eating, scribbling and tantrums.

Dickerson, M.U., Eastman, M.J., & Saffer, A.M. (1984). Child care training for adults with mental retardation: Volume I, Infants. (Available from National Institute on Mental Retardation: York University, Ontario, Canada.)

> This is the first of three manuals and training models for parents with mental retardation with infants. The first volume on infants is divided into six units: Holding, Feeding, Diapering, Bathing, Dressing, and Playing. Each unit consists of simple line drawings and companion instructor's page which includes background information, references, points of emphasis, areas of caution, and specific tips for training or teaching adults with mental retardation. There is an accompanying manual for the parents.

Dickerson, M.U., Eastman, M.J., & Saffer, A.M. (1984). Child care training for adults with mental retardation: Volume II, Toddlers. (Available from National Institute on Mental Retardation: York University, Ontario, Canada.)

> This is the second of three manuals and training models for parents with mental retardation with infants. This volume on toddlers includes sections on mobility, feeding, dressing, bathing, toileting, sleeping, playing and language. Each unit consists of simple line drawings and companion instructor's page which includes background information, references, points of emphasis, areas of caution, and specific tips for training or teaching adults with mental retardation. There is an accompanying manual for the parents.

Family, Infant and Preschool Program. (1989). A parent guide to the family, infant and preschool program. (Available from Western Carolina Center: Morgantown, North Carolina 28655.)

> The program is based upon two beliefs: "That all children and their family members have strengths and capabilities" and "that the best way to support and strengthen children and families is to promote their growth and well-being." A series of family activities are presented: 1) Identifying Your Family's Need for Resources, 2) Identifying Your Family' s Unique Strengths; 3) Identifying Your Family's Personal Network Members, and 4) Writing an Individualized Family Support Plan.

Farran, D., Kasari, C., Comfort, M., & Jay, S. (1986). Parent/caregiver involvement scale. (Available from Child Development and Family Relations, University of North Carolina: Greensboro, NC 27412-5001.)

The Parent/Caregiver Involvement Scale (PCIS) provides a global assessment of the amount and the quality of involvement between a caregiver and a child. Eleven different behaviors are observed for the amount, the quality, and the appropriateness of the interaction: 1) physical involvement, 2) verbal involvement, 3) responsiveness, 4) play interaction, 5) teaching, 6) control over child's activities, 7) directives, 8) relationship among activities, 9) positive and 10) negative emotions, and 11) goal setting. There is an additional section of the scale for a global assessment of caregiver involvement.

Fischer, E. Developing the parenting skills of the mentally handicapped parent. (Available from 337 W. North St., Wooster, Ohio 44691.)

As a description of monthly classes held by Wooster Community Residences, Inc. for parents (and their children) who were described as "MR/DD/Socially impaired," the manual includes a typical class agenda, description of activities, and discussion of outcomes and related services needed by families.

Jageman, L.W. & Meyers, J.E. (1986). Counseling mentally retarded adults: A procedure and training manual. (Available from Materials Development Center, School of Education and Human Services, University of Wisconsin-Stout.)

This manual provides a guide to counseling for adults with mental retardation. The authors provide an overview of counseling needs of adults with mental retardation and a review of the literature concerning counseling effectiveness with their population. They offer chapters discussing different counseling methods and techniques, steps in the counseling process, important counseling skills, counseling approaches that have been effective and adaptations of counseling methods for use with adults.

Lieb, E. & Frey, H. (1989). Basic child care skills in pictures. (Available from Good Samaritan School: 195 Island Park Ave., Defiance, Ohio 43512.)

This manual to assist parents with developmental disabilities in caring for their children consists of photographs concerning the following areas of child care: 1) baby holding; 2) preparation of formula; 3) bottle feeding; 4) solids and vitamins; 5) diapering, diaper pail and laundry; 6) bathing the baby; 7) selection of toys; 8) hazards and; 9) care of the sick infant.

LIFE (Learning Independence through Family Education). (Available from Developmental Services Center: 1304 W. Bradley Ave. , Champaign, IL 61821.)

LIFE is a family life and parenting skills curriculum developed for the non-reading adult with mental retardation. The curriculum includes a training manual and ten activity manuals covering such topics as family planning and contraception, pregnancy and prenatal care; special childcare issues, children's health issues, managing behavior, and adult self-esteem. Each of the manuals can be purchased separately or the curriculum can be purchased in its entirety.

Parenting: Birth - Six for parents with special learning needs.(1988). (Available from American Red Cross: Los Angeles, CA.)

> This manual for parents with mental retardation covers six general principles and offers seven teaching methods. The six units covered are: development, discipline, stimulation, nutrition, health, and safety for the child ranging in age from birth to six years. The seven teaching methods offered include visuals, discussion, exploring parents' feelings, demonstration and practice, observation, activity and practice situations. Outline drawings for use as transparencies are included.

Parks, S. (1984). HELP: When the parent is handicapped. (Available from VORT Corporation: P.O. Box 60880, Palo Alto, California 94306. (415) 322-8282.)

> This guide is an adapted version of the Hawaii Early Learning Profile (HELP) Activity Guide for parents who have disabilities. Alternative parent training activities are included for parents who are mentally retarded, deaf, blind, and physically disabled. Parents' training activities are included to facilitate the development of children who are developmentally within the birth to twenty-four month age range. Issues and suggestions in the following areas are included: cognitive development; expressive language development, gross motor development; fine motor development, social-emotional development; and self help.

Promoting effective parenting: A manual for working with parents with cognitive limitations. (1988). (Available from Cambridge Family and Children's Service: 20 Academy Street, Arlington, Massachusetts 02174. Att. Jan Plager.)

> "The purpose of the manual is to teach the caregiver the essential components of parenting skills. The goal is to work effectively with parents to promote safe and healthy child development, as well as to enhance the parent's level of independence and self-esteem." (p. 5)

Sanford, J. & Wengler, A.K. (1988). Parents P.L.U.S.: Project for Learning and Using Skills. (Available from Franklin County Board of Mental Retardation and Developmental Disabilities: Columbus, Ohio 43219. (614) 475-6440.)

> This manual provides a basic outline of the Parents P.L.U.S. Project which provided training in parenting skills for parents who have developmental disabilities. This manual describes the program which consists of home visits, parenting classes, guided family activities and coordination of family support services. The topics covered in the training sessions included: 1) parenting role and self-esteem, 2) discipline/child development, Part I and Part II, 3) home safety and organization, 4) family health, 5) family planning, 6) nutrition, feeding, meal planning, 7) support systems, resources and 8) summary and family fun activity.

## IV. National Projects

Becoming Independent - Family Life Support. 6555 Hunter Drive #7, Rohnert Park, CA 94928. (707) 584-1655. Contact: Rebecca Herbers.

> The Family Life Support service is an individualized home-based program designed to assist adults with special needs/mental retardation with their parenting and homemaker skills.

Developing the Parenting Skills of Mentally Retarded/ Developmentally Disabled/Socially Impaired Adults. Wooster Community Residences, Inc. 217 East Larwill St., Wooster, OH 44691.

> This is a description of an intervention project/program with parents with mental retardation which would reduce the risk of child abuse or neglect, as well as enhance the parents' ability to stimulate and enrich their child's environment. Group classes for 12 parents (11 children) and their caseworkers were held once a month for a year. In-home visits during the month reinforced the group meeting. Step-by-step demonstrations, role play, audio-visual tapes, films and group discussions were used to convey information on 10 topics: 1) parent child communications, 2) nutrition, 3) discipline, 4) childrens' grooming and hygiene, 5) improving health care, 6) frustration and stress, 7) homemaking skills, 8) birth control, 9) basic first aid and 10) safe environment. A pre-session evaluation and a post-session test were used as assessment tools.

Nekton In-Home Program. 276 N. Snelling Ave., St. Paul, MN 55104. (612) 487-1558. Contact: Dorothy Nelson.

> The Nekton In-Home Family Program (IHFP) provides intensive in-home counseling, teaching, crises intervention and support services to families where one or both parents are mentally retarded and to low functioning families receiving Child Protection Services. The staff also works to increase the parents' abilities to use community resources, improve social network, and upgrade employment where appropriate. The mothers meet every other week for a women's group which focuses on self-esteem, personal care, safety, parenting skills and nutrition. Their young children are provided with nursery care during this time. An evening parenting group meets monthly and a men's group meets twice a month. The families meet as a group five to six times during a month and during the year for parties, picnics and holidays.

Northwest Center Child Development Program. 2919 First Avenue West, Seattle, Washington 98119. (206) 286-2322.

> This program offers center-based full day child care, an in-home program, special education, pediatric, occupational and communication therapies, nutrition counseling, health monitoring and family counseling to families with children, birth through five years of age. The program integrates handicapped and non-handicapped children. The project has developed an outreach training model for mainstreaming children with handicaps in generic programs.

Parent and Child Training Club (P.A.C.T.). Strong Memorial Hospital, 601 Elmwood Ave. Box 650, Rochester, NY 14642. (716) 275-2400. Contact: Ann Glaser, CSW.

> PACT is a multi-service program encompassing physical and psychological needs of families at risk of child abuse or neglect. The program offers comprehensive services during pregnancy and through the first 2 years of the child's life: home visitation, social work intervention, case management, prenatal and pediatric care, crisis intervention, parent support groups, social activities, advocacy and transportation.

Parents and Children Together (P.A.C.T.). 141 South Main Street, Manville, NJ 08835. (201) 725-2266. Contact: Jeanne Guarnieri.

> Parents and Children Together, P.A.C.T., is a community based parenting education program for multi-risk families. This preventive intervention home and center based program assists parents who are developmentally disabled to enhance their capacity to enjoy and nurture their children. In addition, this program strives to increase the parents' ability to independently access and appropriately utilize community resources. Program components include: 1) Home-based Intervention, 2) Parent Support Groups, 3) Developmental Day Care, and 4) Monthly Topical Workshops on Child Development Issues.

Pearl Buck Center: Families with Special Needs. 5100 W. Amazon, Eugene, OR 97405. (503) 345-8506 Contact: Robin Marks-Fife.

> The Families with Special Needs Program provides a preschool for the potentially normal intelligence children of mildly handicapped adults (those with IQ's between 70 and 84). The program provides additional support in the areas of parenting and family issues to the adults.

Project ESPRIT. ARC Allegheny, 1001 Brighton Road, Pittsburgh, PA.

> ARC Allegheny's Project ESPRIT (Educational Systems in Parenting for the Retarded with Infants and Toddlers) enhances parenting and independent living skills for parents who are mentally retarded. The ESPRIT Project develops individual assessment and program plans for each parent and child. In-home and center-based training and parenting and homemaking skills include: budgeting, nutrition, advocacy, crisis intervention, behavior management, mobility training, child development and housekeeping.

Reuben Lindh Learning Center Parenting Program. 3616 12th Avenue South, Minneapolis, MN 55407. (612) 721-5111. Contact: Audrey Kuist.

> This in-center program designed for men and women with developmental disabilities who are parents or are potential parents provides classes and discussion in parenting, self-esteem, support, relationships, cooking, nutrition, health, sexuality, family planning, remedial reading, math, money and time management.

SHARE/UCLA Parenting Program. Neuropsychiatric Institute, 760 Westwood Plaza, Los Angeles, 90024. (213) 206-6150. Contact: Linda Andron or Alexander Tymchuk.

> The SHARE/UCLA Parenting Program has been providing clinical service specifically for parents with mental retardation both within UCLA and in the community along with training and technical assistance to agencies and staffs nationwide as an organized program for the past decade. A major focus has been to empirically-address many of the research and service issues related to working with parents with mental retardation.

## V. Annotated Bibliography

### Chapter One An Early Intervention Model

Booth, C.L., Mitchell, S.K., Barnard, K.E., & Spieker, S.J. (1989). Development of maternal social skills in multiproblem families: Effects on the mother-child relationship. Developmental Psychology, 25(3), 403-412.

> This study assessed a two-step-infant preventive intervention model with 147 multiproblem mothers and their infants. Step 1 of the intervention model was for the mother to improve her interpersonal competence with other adults; step 2 was for her to learn more optimal parenting behaviors. The results partially supported the two-step model: For those women who initially had low social skills, the two-step model improved their competence in relation to other adults and their children. The mothers' active involvement in the program and the therapeutic relationship between the mother and the professional were cited as important features of the model.

Dunst, C.J., Trivette, C.M., & Deal, A.G. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.

> This book presents an indepth, comprehensive overview of underlying principles and guidelines for family systems assessment and intervention procedures. "Enablement" is defined as creating opportunities for all family members to display and acquire competencies that strengthen family functioning. "Empowerment" is defined as "a family's ability to meet needs and achieve aspirations in a way that promotes a clear sense of intra-family mastery and control over important aspects of family functioning." (p. x) The book is divided into eight chapters: 1) Introduction (social system concepts and present beliefs); 2) Needs, Aspirations, and Family Functioning; 3) Resource, Social Support, and Family Functioning; 4) Help-Giver Behavior; 5) Intervention Principles; 6) A Family System's Assessment and Intervention Model; 7) Case Studies; and 8) Family-Level Intervention Plans.

Dybwad, G. (1989, March). Empowerment means power-sharing. TASH Newsletter, 5 & 8.

> Dybwad describes the historical beginnings of empowerment and its meaning today. Empowerment is defined as someone or some organization acquiring or activating power it had not exercised before. The author emphasizes the need for power sharing through a coalition or other support groups as the means for maintaining empowerment that has been attained.

Lyons-Ruth, K., Connell, D.B., Grunebaum, H.U., & Botein, S. (1990). Infants at social risk: Maternal depression and family support services as mediators of infant development and security of attachment. Child Development, 61, 85-98.

> In this study 31 infants at high social risk due to the combined effects of poverty, maternal depression, and caretaker inadequacy were assigned to weekly home-visiting services. At 18 months of age, the home-visited infants were compared with 2 groups of socioeconomically similar unserved infants on measures of infant

development, infant attachment, mother-infant interaction, maternal depression, and maternal social contacts. Results of the study supported the benefits of developmentally oriented home-visiting services for infants at greatest risk.

National Institute of Handicapped Research-Office of Special Education and Rehabilitative Services. (1984). Disability and families: A family systems approach. Rehab Brief: Bringing Research into Effective Focus, 7 (9).

This Rehabilitation Brief describes the major elements of the Family Systems Theory that might be utilized in working with families who have members with disabilities.

Turnbull, A.P., & Turnbull, H.R. (1985). Stepping back from early intervention: An ethical perspective. Journal of the Division for Early Childhood, 10 (2), 106-117.

The authors address the ethical implications of three early intervention issues: 1) the fix-it approach inherent in early intervention when it is carried to the extreme; 2) the negative or pathological focus of the impact of a child with a disability on the family; and 3) treatment and non-treatment of newborns with disabilities and the associated use of amniocentesis to identify birth defects during fetal development as a prelude to a decision on abortion.

Tymchuk, A., Andron, L., & Unger, 0. (1987). Parents with mental handicaps and adequate child care - a review. British Institute of Mental Handicap, 15, 49-53.

This article discusses current issues concerning individuals with mental retardation as parents. The authors call for additional research that addresses the following parenting issues: What are the predictors of adequate parenting? What types and frequency of training are useful? How do other factors such as emotional disturbance, stress, and health-related problems influence acquisition and maintenance of parenting skills?

## Annotated Bibliography

### Chapter Two

### Understanding of Parents with Special Needs Mental Retardation

Booth, C.L., Mitchell, S.K. Barnard, K.E., & Spieker, S.J. (1989). Development of maternal social skills in multiproblem families: Effects on the mother-child relationship. Developmental Psychology, 25(3), 403-412. (Annotation under Chapter One)

Cansler, D.P., Martin G.H., & Valand, M.C. Working with families: A manual for early childhood programs serving the handicapped. Chapel Hill, NC: Chapel Hill Training Outreach Project.

> This excerpt describes three strategies, the nonproblem approach, the situational approach and the cognitive approach as valid approaches to meet the needs of families with whom traditional approaches fail.

Espe-Sherwindt, M., Kerlin, S., & Oppenheimer, S. (1987). Parents who are mentally retarded: Attitudes, intervention, and collaboration. Unpublished manuscript, University Affiliated Cincinnati Center for Developmental Disorders, Cincinnati, Ohio.

> The authors present a model early intervention program for babies with or at risk for developmental disabilities born to high-risk parents. They explore the basic problems and need areas faced by these families, as well as some common stereotypes of professionals working with these families. Guidelines are presented for providing early intervention with these infants and families, as well as a method for facilitating change through social support and crisis intervention.

Feldman, M.A., Towns, F., Betel, J., Case, L., Rincover, A., & Rubino, C.A. (1986). Parent Education Project II. Increasing stimulating interaction of developmentally handicapped mothers. Journal of Applied Behavior Analysis, 19, 23-37.

> This is a report on two studies involving assessment and training of parent-child interactional skills in mothers with developmental handicaps. Study 1 compared the interactions of eight mothers with handicaps versus eight mothers without handicaps during play with their children. Study 2 provided training to offset the deficits found in the vocal and praise behavior of the mothers with handicaps. The training resulted in an increase in the vocal and praise behaviors, as well as a generalization of these skills to the home environment.

Ferretti, R.P. (1989). Problem solving and strategy production in mentally retarded persons. Research in Developmental Disabilities, 10, 19-31.

> The information presented offers evidence that children with mental retardation can, contrary to historical research, learn generalizable problem-solving skills. Several

studies are described with results showing that when given instruction in strategies, persons with mental retardation can and do use problem-solving skills.

Gilson, S.F., & Levitas, A.S. (1987). Psychosocial crises in the lives of mentally retarded people. Psychiatric Aspects of Mental Retardation Reviews, 6 (6), 27-32.

This article proposes 15 developmental milestones in the lives of individuals with mental retardation and suggests that these milestones represent crises marked by emotional turmoil in the lives of these individuals. The milestones set forth are: 1) confirmation of the diagnosis of mental retardation, 2) birth of siblings, 3) starting school, 4) the onset of puberty and adolescence, 5) sex and dating, 6) being surpassed by sibling, 7) emancipation of siblings, 8) the end of education, 9) out-of-home placement, 10) establishment of staff/client relationships, 11) inappropriate expectations, 12) aging, illness and death of parents, 13) death of peers, loss of friends, 14) medical illness, and 15) psychiatric illness.

Heighway, S.M., & Kidd-Webster, S. (1988, September). Supported parenting: Promoting the welfare of children whose parents are mentally retarded. Update-National Resource Institution on Children and Youth with Handicaps.

This brief article calls for extending community services and support for parents with mental retardation. The article discusses criteria for identification and suggests modification of present community services provided.

Heighway, S.M. , Kidd-Webster, S., & Snodgrass, P. (1988, November-December). Supporting parents with mental retardation. Children Today, 24-27.

This article addresses the need to understand the needs of parents with mental retardation. The Positive Parenting Project of Brown County, Wisconsin in which professionals provide in-home, individualized and intensive case management services for families is described. Emphasis is placed on parenting skills and accessing community resources. Results of this project are discussed.

Laman, D.S., & Reiss, S. (1987). Social skill deficiencies associated with depressed mood of mentally retarded adults. American Journal of Mental Deficiency, 92 (2), 224-229.

Specific social skill deficiencies associated with depressed mood were identified in a group of 45 adults with mental retardation with mixed or no psychiatric diagnoses. Self-report and informant-rated measures of social skills, social support, and depressed mood were obtained. One set of results replicated previous findings that high level of depressed mood are associated with poor social skills and low levels of social support. Another set of findings identified 30 social skill deficits associated with depressed mood. The subjects with depressed mood were withdrawn and interacted less with others; their social interactions were more inappropriate and ineffective. Some instances of antisocial behavior might be motivated by depressed mood.

Lynch, E.W., & Bakley, S. (1989). Serving young children whose parents are mentally retarded. Infants and Young Children, 1 (3), 26-38.

This article focuses on the issues that emerge and the support systems that are required when adults who are mentally retarded choose to become parents. It briefly reviews the literature on the cognitive and social/emotional characteristics associated with mental retardation, the literature on parents with mental retardation, and the interaction between these characteristics and issues in relation to child abuse and neglect. Three case studies in which one or more of the parents are mentally retarded are presented to illustrate the range of problems and needs that parents with mental retardation have as they try to parent effectively. The article concludes with recommendations for service providers who work with parents who are mentally retarded. (Abstract)

McGee, J.J., Menolascino, F.J., Hobbs, D.C., & Menosek, P.E. (1987). Gentle teaching: A non-aversive approach to helping persons with mental retardation. New York, NY: Human Services Press.

This book offers a value base and methodology for working with persons with mental retardation. The authors focus on bonding as the means to achieve "gentle teaching. Three interactional processes to be taught to persons with mental retardation are discussed: 1) That our presence signals safety and security; 2) that our words and contact (e.g. , looks, smiles, embraces, touch, etc.) are inherently rewarding; and 3) that participation yields reward.

Murphy, A. Assessing and planning for cognitively limited parents. Unpublished manuscript, Developmental Education Clinic, The Children's Hospital: Boston.

This manuscript focuses on a project of the Developmental Evaluation Clinic of the Children's Hospital in Boston which evaluated parents' intellectual and psychosocial capabilities, as well as their parental competency. The Developmental Educational Clinic then worked with the parents and involved agencies to help them develop appropriate goals. The authors discuss the need for agencies to coordinate activities and to adapt services to meet the needs of the population.

Musick, J.S., Stott, F.M., Spencer, K.K., Goldman, J., & Cohler, B.I. (1984). The capacity for "enabling" in mentally ill mothers. Zero to Three, 4(4), 1-6.

This article describes the results of a treatment rehabilitation program for mentally ill mothers conducted by Chicago-based Thresholds Mothers Project. Included in this program was a therapeutic nursery program for the child, ongoing evaluation and clinical efforts focused on the mother-child relationship and involvement and treatment of the larger family system. Results indicated success depended on a constellation of maternal factors that seemed to be related to the child' s capacity to seek and use growth-fostering influences beyond his mother's orbit. The authors termed this constellation "enablement." The children who improved were those whose mothers enabled them to turn to significant others within the therapeutic nursery environment, and to "use" positively what was offered to enhance their own development.

Peterson, S.L. , Robinson, E.A., & Littman, I. (1983). Parent-child interaction training for parents with a history of mental retardation. Applied Research in Mental Retardation, 4, 329-342.

This report describes parent-child interaction among families with a history of parental retardation and explores the modification of this interaction through parent training. Six parents attended eight small group sessions designed to teach relationship building skills. Results suggested that parents with mental retardation can acquire subtle attentional skills, but that they continue to use only the nondirective skills (not positive verbal behavior) when training is discontinued.

Reiss, S., Levitan, G.W., & McNally, R.J. (1982). Emotionally disturbed mentally retarded people: An under served population. American Psychologist, 37, (4), 361-367.

The need to increase the supply of psychotherapeutic services for the emotional problems of people with mental retardation, as well as those of people with IQS between 70 and 80, is discussed. Low intelligence may increase the risk of emotional disturbance because it creates special adjustment problems. Low intelligence may decrease the opportunity for adequate psychotherapeutic services because of administrative, conceptual, and attitudinal reasons. It is suggested that clinical psychologists can play an important role in developing the needed services.

Schilling, R.F., & Schinke, S.P. (1984). Maltreatment and mental retardation. Perspectives and Progress in Mental Retardation, 1, 11-21.

The authors discuss the relationship between mental retardation and maltreatment with respect to children with mental retardation, persons with mental retardation living in the community and children of parents with mental retardation. The effects of socioeconomic status are discussed. An intervention program for parents with mental retardation is presented.

Schilling, R.F. , Schinke, S.P., Blythe, B.J., & Barth, R.P. (1982). Child maltreatment and mentally retarded parents: Is there a relationship? Mental Retardation, 20(6), 201-209.

This paper reviews the child protection and mental retardation literature on the relationship between parents' intelligence and maltreatment of children. The weaknesses and flaws in these studies are discussed. The author suggests four areas for future investigation: 1) the influence of social class; 2) how intelligence relates to the multitude of variables which constitute childbearing; 3) factors leading to successful parenting by mentally retarded persons, and 4) intervention with parents who have mental retardation.

Turnbull, A.P., & Turnbull, H.R. (1985). Stepping back from early intervention: An ethical perspective. Journal of the Division for Early Childhood, 10 (2), 106-117. (Annotation under Chapter One).

Tymchuk, A. J. (In press) Depression symptomatology in mothers with mental retardation. American Journal of Mental Retardation.

> "The present study examined the prevalence of depression symptomatology in mothers with mental retardation in comparison to that found in a group of contrast mothers. The results showed that not only is that prevalence greater in the former group, but also the pattern of symptoms is different and of a more severe nature. These symptoms too were found to be related to different maternal, parental, child and family variables in the two populations." [Abstract]

Tymchuk, A.J. (1985). Effective decision making for the developmentally disabled. Portland, OR: Ednick Communication.

> This book is designed to train the person with developmental disabilities to make thoughtful decisions. The book is intended for use by parents working with their child with a developmental disability and by professionals working with persons with developmental disability. The concepts presented are those that are considered to be the most critical for anyone to make effective decisions.

Tymchuk, A. J. (In press) Self -concepts of mothers with mental retardation. Psychological Reports.

> This study compared the self concepts (the Tennessee Self-Concept Scale) of 27 mothers with mild mental retardation with 95 mothers whose children attended daycare in the same locale. The results indicated that the mothers with mental retardation scored significantly lower on all sub-scales of the test of self-concept in comparison to the contrast group. In addition, the results indicated that where 72% of the normal group scored above a suggested cutoff indication of a positive self-concept, only 33% of the parents with mental retardation did.

Tumchuk, A. J., Andron, L., & Rahbar, B. (1988). Effective decision-making/problem-solving training with mothers who have mental retardation. American Journal on Mental Retardation, 92 (6), 510-516.

> Mothers with mental retardation received group training in decision-making using vignettes describing child-raising situation. A multiple baseline procedure was used to assess the effectiveness of training in how to identify and apply decision-making steps to trained and untrained situational vignettes. Significant changes in step identification and use were observed and maintained for a month for both types of vignettes. Although training included nothing to improve the appropriateness of decisions, there was significant improvement for the high-risk situations used in training. Results suggest that parents with mental retardation are able to learn to apply basic steps of decision-making.

Tymchuk, A.J., Andron, L., & Unger, 0. (1987). Parents with mental handicaps and adequate child care - a review. Mental Handicap, 15, 49-53. (Annotation under Chapter One)

Tymchuk, A.J., & Andron, L. (1988). Clinic and home parent training of a mother with mental handicap caring for three children with developmental delay. Mental Handicap Research, 1(1), 24-38.

> This study reports on parent training efforts with a mother of 3 children, each with behavioral and/or medical and cognitive delays. Training occurred first in a clinic setting and then in the home. Using a multiple baseline procedure the results showed that the interactions were positively changed in both settings ... The data support the contention that mothers with mental handicaps can be successfully trained to care for several (even delayed) children. Given the manifold problems of the mother studied and of other mothers with similar handicaps, and the consequent large expenditure of professional effort, it is apparent that other training programs should be examined. [Abstract]

Wolraich, M.L., & Siperstein, G.N. (1983). Assessing professionals' prognostic impressions of mental retardation. Mental Retardation, 21(1), 8-12.

> Attitudes of pediatricians, psychologists, educators, allied health professionals, and social workers toward mental retardation are compared by assessing their prognostic impressions of mental abilities required for various tasks. The results showed that pediatricians were significantly more pessimistic about the ultimate abilities of adults with mental retardation than psychologists and educators. Suggestions for defining and clarifying the nature of the differences are advanced.

Zetlin, A.G., Wersner, T.S., & Gallimore, R. (1985, April). Diversity, shared functioning, and the role of benefactors: A study of parenting by retarded persons. In S.K. Thurman (Ed.), Children of handicapped parents: Research and clinical perspectives (pp. 69-95). Orlando, Florida: Academic Press.

> The authors discuss the metamorphosis of a therapy group for de-institutionalized mothers with mental retardation. The mothers influence the professionals to broaden their program to encompass a greater breadth and depth of experience.

## Annotated Bibliography

## Chapter Three

## Intervention Principles and Strategies

Allen, D.A., Affleck, G., McGrade, B., & McQueeney, M. (1984, December). Factors in the effectiveness of early childhood intervention for low socioeconomic status families. Education and Training of the Mentally Retarded, 254-260.

> The obstacles to early intervention with lower SES families are reviewed. Alternatives for the lower SES family are proposed: integration of non-verbal training in the family's normal routine, greater program flexibility respecting socio-cultural differences in parenting styles, the incorporation of more information on child development and expectations, and provision of ways in which to alleviate environmental concerns.

Andrews, S.R., Blumenthal, J.B., Johnson, D.I., Kahn, A.G., Ferguson, C.J., Lasater, T.M., Malone, R.E., & Wallace, D.B. (1982). The skills of mothering: A study of parent child development centers. Monographs of the Society for Research in Child Development, 47(6).

> This monograph reports the results of the Parent Child Development Center (PCDC) experiment begun in 1970 by the U.S. Office of Economic Opportunity. This project focused on promoting the development of young children from families with low-income through helping parents become more competent at rearing their children. Comprehensive supportive services for both parent and child were provided, and significant differences between program and control groups emerged.

Abraham, C. (1989). Supporting people with a mental handicap in the community: A social psychological perspective. Disability, Handicap & Society, 4 (2), 121-130.

> The sociological meaning of 'community' is examined in relation to the need to create relationships within which people with a mental handicap can develop positive social and personal identities. The creation of artificially maintained supportive networks is recommended and the resource implications of achieving good-quality care in the community are noted.

Bailey, D.B., Simeonsson, R.J., Winton, P.J., Huntington, G.S., Comfort, M., Isbell, P., O'Donnell, K.J., & Helm, J.M. (1986). Family focused intervention: A functional model for planning, implementing, and evaluating individualized family services in early intervention. Journal of the Division for Early Childhood, 10(2), 156-171.

> This article describes a functional model for assessing family needs, specifying family goals, implementing family services, and evaluating effectiveness. The model draws on the "goodness-of-fit" concept to individualize family services in order to optimize the "fit" between family, child, and services provided.

Baldwin, S. (1985). Models of service delivery: An assessment of some applications and implications for people who are mentally retarded. *Mental Retardation*, *23*(1), 6-12.

> This paper discusses 5 models for working with and delivering services to people who are mentally retarded: 1) Child development model, 2) medical model, 3) socio-ecological model, 4) behavioral model, 5) psycho-educational model. A comparison between these models is suggested, together with an analysis of their effects, strengths, and possible weaknesses.

Berger, M., & Fowkles, M.A. (1980, May). Family intervention project: A family network model for serving young handicapped children. *Young Children*, 22-32.

> This article provides the rationale for and a model of family-focused early intervention. The information is based on an early intervention program for children with handicaps from birth to age four and their families.

Brantlinger, E.A. (1988). Teachers' perceptions of the parenting abilities of their secondary students with mild mental retardation. *Remedial and Special Education*, *9*(4), 31-43.

> This article discusses the perceptions of teachers regarding the parenting aspirations and abilities of their secondary students considered to be educable mentally retarded. Teachers believe most of the students expect to marry and have children. The students were perceived as varying in their ability to assume the role of parent. Sexuality, social relationships and parenting classes are recommended.

Brechin, A., & Swain, J. (1988). Professional/client relationships: Creating a 'working alliance' with people with learning difficulties. *Disability, Handicap & Society*, *3*(3), 213-226.

> This paper explores the nature and implications of existing professional approaches, and the growing awareness of the importance of professional/client relationships. It considers how new styles of relationships might be defined and generated. The impact and implications of self-advocacy and normalization are explored.

Bromwich, R. M. (1985). "Vulnerable infants" and "risky environments." *Zero to Three*, *6*(2) 7-12.

> This article discusses difficulties surrounding interaction between vulnerable infants and their parents, infants who are biologically vulnerable facing the compounding problem of environmental risk, and the intervention program of the UCLA Infant Studies Project. "Experience with high-risk infants in poverty families dictates that before an intervention can be focused on parent-infant interaction, the total situation must be assessed and the areas of greatest stress and the most immediate, critical needs of parents and family must be identified jointly with the parents." (p. 9) Parents with mental retardation and their childrens' development is also discussed with suggestions for programs which will enhance the childrens' development.

Chamberlain, B.S., Jageman, L.W., & Mullins, V.L. (1988, November). *Counseling Persons with Mental Retardation*. Unpublished manuscript, Ohio University and Gallipolis Developmental Center.

This is a compilation of descriptive diagrams of several aspects of a counseling program for persons with mental retardation: a list of assets of persons with mental retardation; a list of options for coping with the barriers to counseling persons with mental retardation; a counseling cycle diagram; a list of counseling skills used in the counseling process; a statistical compilation of counseling methods used by 56 teachers of students with mild mental retardation or learning disabilities; a statistical compilation of counseling methods applied by 104 staff working with persons with moderate and severe mental retardation and; decision factors and steps in choosing a counseling method.

Deffenbacher, J.L. (1985). A cognitive-behavioral response and a modest proposal. The Counseling Psychologist, 13(2), 261-269.

The role and importance of the client-counselor relationship as it exists across all type of counseling and psychotherapy is explored. "Relationship" is seen by the author as the need to build rapport, lessen interpersonal anxiety in the relationship, increase trust and build an interpersonal climate in which clients can openly discuss and work on their problems.

Espe-Sherwindt, M. Final progress report: Early identification and intervention for high-risk infants and families. Unpublished manuscript, University Affiliated Cincinnati Center for Developmental Disorders, Cincinnati, Ohio.

This report focuses on a model early intervention program to provide comprehensive services to infants with developmental disabilities/delay who also have high-risk families unable to utilize existing community resources. Program design, implementation and evaluation, as well as professional training are discussed.

Fantuzzo, J.W., Wray, L., Hall, R., Goins, C., & Azar, S. (1986). Parent and social-skills training for mentally retarded mothers identified as child maltreaters. American Journal of Mental Deficiency, 91(2), 135-140.

The effectiveness and generality of a parent- and social-skills training program for three mothers with mild retardation identified as child maltreaters were investigated. The program was conducted by one trainer in a community-based facility and included the following components: (a) individualized performance standards, (b) response-specific feedback, (c) self-monitoring, and (d) group rewards. A multiple-baseline design across parenting- and social-skill areas was used to evaluate the training. A findings revealed that the game contingencies effectively increased the mothers' ability to identify the most effective action to take in common problematic parenting and social situations. Generalization and recidivism data supported the efficacy of treatment gains. (Abstract)

Feldman, M.A., Case, L., Towns, F., & Betel, J. (1985). Parent Education Project I: Development and nurturance of children of mentally retarded parents. American Journal of Mental Deficiency, 90(3), 253-258.

The development and home environments of 12, 2-year-old children raised by mentally retarded mother were assessed using the Bayley Scales of Infant Development and the Caldwell Home Observation for Measurement of the Environment (HOME) Inventory. Results indicated that the children were at-risk for developmental delay, particularly in language. The child's cognitive development was significantly correlated with (a) whether the mother had a previous child removed from the home by child protection authorities and (b) HOME Inventory total scores. Analysis of HOME subscales revealed that mothers who were involved, responsive, and restrictive and punishing had children with higher Bayley Mental Development Index scores. (Abstract)

Heighway, S.M., Kidd-Webster, S. & Snodgrass, P. (1988, November-December). Supporting parents with mental retardation. Children Today, 24-27. (Annotation under Chapter Two)

Hoy, C. (1986). Preventing learned helplessness. Academic Therapy, 22 (1), 11-18.

This article outlines ways in which professionals can help their students with learning disabilities overcome learned helplessness: sharing responsibilities with students; sharing information on strengths and weaknesses; learning self-advocacy; learning decision making; setting goals; solving programs; modeling responses and changing attitudes.

Lynch, E.W. , & Bakley, S. (1989). Serving young children whose parents are mentally retarded. Infants and Young Children, 1 (3), 26-38. (Annotation under Chapter Two).

Madsen, M.K. (1979, August). Parenting classes for the mentally retarded. Mental Retardation, 195-196.

This is a brief description of a 5 week parenting course for parents with mental retardation. The description includes Classes I-V, a "Parenting Kit," classes for the children, evaluation methods, and recruitment sources.

McGee, J.J., Menolascino, F.J., Hobbs, D.C., & Menousek, P.E. (1987). Gentle teaching: A non-aversive approach to helping persons with mental retardation. New York, NY: Human Sciences Press. (Annotation under Chapter Two).

Peterson, S.L., Robinson, E.A., & Littman, I. (1983). Parent-child interaction training for parents with a history of mental retardation. Applied Research in Mental Retardation, 4, 329-342.(Annotation under Chapter Two).

Pomerantz, P., Pomerantz, D.J., & Colca, L.A. (1990). A case study: Service delivery and parents with disabilities. Child Welfare, 69(1), 65-73.

A Specialized Family Program, through a supervised paraprofessional, provided time-intensive, home-based service to a family in which both parents were deinstitutionalized disabled individuals. Interventive procedures consisted of systematic educational procedures in basic child care and home management and the case management of many active but uncoordinated agencies. Through this case

history, the programmatic needs of parents with disabilities and their families are discussed, with emphasis on (1) an orientation of family support and advocacy; (2) active, home-based intervention; (3) educational methods based on systematic, behaviorally based instruction; (4) coordination of all workers involved; and (5) client control of decisions related to intervention.

Rosenberg, S.A., & McTate, G.A. (1982). Intellectually handicapped mothers: Problems and prospects. Children Today, 24-26.

This article describes the Intensive Services to Families at the Risk Project at the University of Nebraska Medical Center working with parents with and without mental retardation who had been referred for serious parenting problems. Weekly home visits, group meetings and referrals to other agencies were provided through the project. The results of the program and recommendations for future services are presented.

Sakata, R.T. (1984). Adult Education: Theory and Practice. (Outreach Series Paper #2). Chapel Hill, NC: Technical Assistance Development System (TADS). [Available from: National Early Childhood Technical Assistance System (NEC*TAS), Frank Porter Graham Child Development Center, CB 8040, 500 NCNB Plaza, Chapel Hill, NC 27599, (919) 962-2001].

Principles of adult theory and education are presented in this publication.

Tymchuk, A.J., & Andron, L. (1988). Clinic and home parent training of a mother with mental handicap caring for three children with developmental delay. Mental Handicap Research, 1, 24-38. (Annotation under Chapter Two).

Tymchuk, A.J., & Andron, L. (in press). Project Parenting: Child interactional training for mothers with mental handicap. Mental Handicap Research.

This two-part study looks at the behavior of nine mothers with mental retardation towards their children compared to that of a contrast group of mothers and the effect of training (to praise, label, and model behavior), on the behavior of mothers with mental retardation toward their children. It was found that for the mothers with mental retardation praising and labeling, as well as the other targeted behaviors, increased after training. However, several mothers learned slowly and lost their gains after a month's follow-up. The results are discussed.

Tymchuk, A.J., Hamada, D., Andron, L., & Anderson, S. (in press). Home safety training with mothers who are mentally retarded. Education and Training in Mental Retardation, 25, 142-149.

This article presents a study involving the training of mothers with mental retardation to understand and implement safety precautions.

Tymchuk, A.J., Hamada, D., Andron, L. & Anderson, S. (In press). Training mothers with mental retardation to respond to common home emergencies. Child and Family Behavior Therapy.

This article presents a study involving the training of mothers with mental retardation how to respond to home emergencies.

Tymchuk, A. J., Andron, L. & Rahbar, B. (1988). Effective decision-making/problem-solving training with mothers who have mental retardation. American Journal on Mental Retardation, 92 (6), 510-516. (Annotation under Chapter Two).

Wayne, F. & Fine, S.B. (1986, April). Group work with retarded mothers. Social Casework: The Journal of Contemporary Social Work, 195-202.

The authors discuss the metamorphosis of a therapy group for mothers with mental retardation who have been deinstitutionalized. The mothers influence the professionals to broaden their program to encompass a greater breadth and depth of experience.

Winton, P.J. (1988). Effective communication between parents and professionals. In D.B. Bailey & R.J. Simeonsson (Eds.), Family assessment in early intervention (pp. 207-228). Columbus, OH: Merrill Publishing.

The author describes the way in which attitudes, cultural beliefs and assumptions create barriers to effective communication. The key communication skills of effective listening, effective questioning, reflection of feelings and content are discussed.

## Annotated Bibliography

## Chapter Four

## Evaluating Progress

Bailey, D.B., & Simeonsson, R.J. (1988). Family assessment in early intervention. Columbus, OH: Merrill Publishing.

> This book "examines issues related to the systematic assessment of families strengths and needs and describes characteristics of various family assessments, identifies considerations in selecting and using family assessment, and proposes an approach to the development of family goals." Chapters 3, 4, 5, 7 & 9 are highly recommended.

Bickman, L., & Weatherford, D.L. (Eds.) (1986). Evaluating early intervention programs for severely handicapped children and their families. Austin, TX: PRO-ED.

> This volume contains several chapters that explain the need for evaluating and how to go about planning an evaluation strategy. There are several excellent tables that outline questions program staff should consider while planning and carrying out evaluation.

Budd, K.S., & Greenspan, S. (1985). Parameters of successful and unsuccessful interventions with parents who are mentally retarded. Mental Retardation, 23(6), 269-273.

> This article discusses parental behaviors that increase the likelihood of difficulties for families. Suggestions to assist parents to alter their behavior are offered.

Deal, A.G., Dunst, C.J., & Trivette, C.M. (1989). A flexible and functional approach to developing Individualized Family Support Plans. Infants and Young Children, 1(4), 32-43.

> A flexible and functional approach to writing and implementing Individualized Family Support Plans (IFSPs) is described. The approach is derived from a needs-based family system model of assessment and intervention. The systems model and approach to developing IFSPs are designed to enable and empower families to become more capable of mobilizing resources to meet their needs in ways that support and strengthen child, parent, and family functionings. (Abstract)

Ferretti, R.P. (1989). Problem solving and strategy production in mentally retarded persons. Research in Developmental Disabilities, 10, 19-31. (Annotation under Chapter Two)

Maher, C.A. (1983). Goal attainment scaling: A method for evaluating special education services. Exceptional Children, 49(6), 529-535.

> Goal Attainment scaling (GAS) is described as useful for evaluating special education services at the local education agency (LEA) level. Utilization of the

approach allows for individualization of program goals for a range of special education service programs. The nature and scope of the GAS method are described.

Matson, J.L., Helsel, W.J., Bellack, A.S., & Senatore, V. (1983). Development of a rating scale to assess social skill deficits in mentally retarded adults. Applied Research in Mental Retardation, 4, 339-407.

This article describes two studies which helped the researchers develop a Social Performance Survey Schedule for adults with mental retardation. The items were arranged into four key factors in social skills: appropriate social skills, poor communication skills, inappropriate assertion, and sociopathic behaviors. Many of these items were used to develop the List of Behavioral Descriptors for this manual.

National Center for Clinical Infant Programs. (1986). Program evaluation: Issues, strategies and models. (Available from National Maternal and Child Health Clearinghouse: 38th & R. Streets, NW, Washington, DC 20057).

This booklet presents topics for discussion for administrators and practitioners serving infants and toddlers at risk and their families. It contains addresses by Dr. Kathryn Barnard on "Major Issues in Program Evaluation," Dr. Victoria Seitz on "Evaluation Strategies," and Dr. Jeree Pawl, "The Infant-Parent Program at San Francisco General Hospital," as well as the summary of a discussion among service providers, state agency administrators and researchers.

Neisworth, J.T. & Fewell, R.R., (Eds.) (1990, Spring). Topics in Early Childhood Special Education. Austin, TX: Pro-Ed.

The spring issue of this quarterly publication presents 8 articles concerning the gathering of family information including the procedure, products and precautions to be taken. The articles and authors are as follows:

1) Mahoney, G., O'Sullivan, P. & Dennebaum. Maternal perceptions of early intervention services: A scale for assessing family-focused intervention.
2) Trivette, C., Dunst, C., Deal, A., Hamer, A.W., & Propst, S. Assessing family strengths and family functioning style.
3) Sexton, D., Thompson, B., Scott, R., & Wood, T. Measurement characteristics of the inventory of parent experience scales.
4) Whitehead, L., Deiner, P., & Toccafondi, S. Family assessment: Parent and professional evaluation.
5) Winton, P., & Bailey, D. Early intervention training related to family interviewing.
6) Summers, J., Dell'Oliver, C., Turnbull, A., Benson, H., Santelli, E., Campbell, M., & Siegel-Causey, E. Examining the individualized family service plan process: What are family and practitioner practices?
7) Able-Boone, H., Sandall, S., Loughry, A., & Frederick, L. An informed, family-centered approach to Public Law 99-457: Parental views.
8) Hanson, M., Lynch, E., & Wayman, K. Honoring the cultural diversity of families when gathering data.

Rotter, J.B. (1966). Generalized expectations for internal versus external control of reinforcement. Psychological Monographs: General and Applied, 80 (1), 1-28.

> This article offers an in-depth explanation of internal and external locus of control. It defines these concepts from the results of experimentation and describes the characteristics of a person who has a strong belief that he or she can control their own destiny. These include: (a) being more alert to those aspects of the environment which provide useful information for future behavior, (b) taking steps to improve environmental conditions, (c) placing greater value on skill or achievement and concern with ability, and (d) being resistive to attempts to influence behavior.

Selig, A.L., & Berdie, J. (1981). Assessing families with a developmentally delayed/handicapped child. Developmental and Behavioral Pediatrics, 2(4), 151-154.

> This article highlights the need for assessment of the entire family, the need to prepare the family for this assessment, the basic parameters of the assessment itself, and two possible resources for family therapy.

Simeonsson, R.J. (1988). Evaluating the effects of family-focused intervention. In D.B. Bailey & R.J. Simeonsson (Eds.), Family assessment in early intervention (pp. 251-267). Columbus, OH: Merrill Publishing.

> This chapter discusses the importance of evaluation in early intervention with families of children with handicaps. The author focuses on procedural considerations in evaluation, the evaluation of parents satisfaction, and evaluation of parent satisfaction, and evaluation procedures and methods.

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